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Storied moments:
A visual narrative inquiry of aboriginal women living with HIV.

by

Vera Franziska Julianne Caine

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A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Nursing.

Faculty of Nursing

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The undersigned certify that they have read, and recommended to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled *Storied moments: A visual narrative inquiry of aboriginal women living with HIV* submitted by *Vera Franziska Julianne Caine* in partial fulfillment of the requirements for the degree of *Master of Nursing.*

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abstract

This visual narrative inquiry tells the stories of five urban aboriginal women living with HIV and in telling their story tells part of our story and part of my story. Throughout this study we attempted to understand the complex, multi-layered stories of despair, struggle, hope and possibility. As well, we tried to make sense of our identity. In these stories there is a continuous shift between the present, past and future, between the known and unknown, between the told and untold, and between the self and others. Visual narrative inquiry combines the use of storytelling with photography to express life experiences. The women utilized disposable cameras during the study to visually document their everyday lives. Visual narrative inquiry helped us explore our life experiences in a relational context whereby the aboriginal women and myself became co-researchers and ultimately co-authors in the writing of stories and visual representation of our lives.

acknowledgements

Tammy, Debbie, Debra, K. and Deanna, I remain in awe of your lives and all its challenges and opportunities. I cannot express the deep felt gratitude to you for having welcomed me into your lives and to have shared your stories and pictures with me; for giving me the opportunity to try and understand your lives and for your braveness to speak with your heart, spirit and mind.

Brenda, thank you for the long telephone conversations, but most of all for helping me untangle knots that seemed impossible to untangle at times and for your friendship. Jean, thank you for breathing life into my understanding and for letting me gently explore my own past, present and future. Linda, thank you for your calm presence and encouragement and for sharing your family stories. Judy, thank you for providing me with a space in which I was able to explore at my own pace.

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Most of all I want to thank my family, my parents, my sister, my brother and my husband, without your unconditional love and support and your belief in my abilities I would have never even begun to undertake this work.

Without the financial assistance of Health Canada, HIV/AIDS Policy Division this work would have been impossible. Thank you, for believing that as a novice researcher I would have the ability to undertake this work.

Vera in relation with

Tammy, Debbie, Debra, K. & Deanna.

preface

This work was created to bring life to a vision of hope and possibility and to bring respect for and recognition to aboriginal women living with HIV.

This work was also created as a tool:

to educate others and as such inform …

to stimulate a dialogue and as such engage …

to inspire people to (re)look at the ordinary and beyond…

to understand and learn to look again …

(Re)told in this book are fragments of a story, moments lived, seen and heard over the past twelve months. By no means is this work complete; indeed it is best described as an unfinished project. Some stories are unintentionally omitted and others by choice, so we ask you to be patient and to listen and look for the untold, to pay attention to your own stories that are narrated as you read.

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the story began long ago

I remember the days at home when I rode my bike along the paths in the fields and from there into the forest … sometimes, just sometimes I can still smell the freshly cut hay fields, taste the wild blueberries in my mouth, and feel the wind around my face. As I sit here, I wonder what it would be like today at this moment to go back and I wonder why it is that I remember with such vividness the smell, the taste and the touch ... It has been almost 12 years now. Sometimes I am confused when people call me an immigrant woman, because that is and that is not, who I am. I remember when I first came to this unfamiliar place, full of adventure, ignorant to the pain that would soon became part of my life. Everyone seems to know I am an immigrant woman – after all the children reassure me that I talk funny.

It's been a long time ago, but so are many of the stories and moments that have shaped who I am today … it is in these stories and re-storied moments that I begin to make sense of my life…

It was my first time in the Northwest Territories and I was off to work in a small isolated community. With weeks of preparation behind me I knew challenges and opportunities were ahead of me. Sitting in a small airplane flying further north and west than I had ever been I asked myself: What would it be like? … Why was I doing this? I was reminded of my last journey where I flew further west and north than I had ever been at that time.

Luckily I met Johnny on the air plane – "Yah, we heard about you" … then there was silence … "look some caribou" … "oh, I missed them" I said, my eyes were not yet trained to distinguish between the different autumn browns and yellows and those of caribou – my eyes were too accustomed to the grays of the city where I had been living for the last few years. That was the extent of our conversation – what did I expect him to say? I began to realize things were going to be different from now on.

We landed safe and sound as we would many times thereafter on the small airstrip just south of the community. This was the beginning of my first experience in the north. I am thankful I came and am still filled with dreams to return to this now familiar place.

I remember the first cold day, the first snowflakes of the year. I wondered about winter and how early the evening sun would set. But that isn't what I remember most about that day. It was Lena's court trial that stands out. The court trial was public and juried. Lena had charged David with rape. Lena was fourteen when the incident occurred, naïve about sexual issues, and a virgin. David on the other hand had a history of sexual assaults and was in his late 20s. I had never met either one of them and didn't know much about the incident. The other nurses I work with urge me to attend the trial; after all it was a "social event" from which I could probably learn something. I still wonder about the word social event and I remember how hesitant I was to go to the trial.

As soon as the trial began it became clear very quickly that Lena received little support from her family or community, and I am not even sure if she had ever met her lawyer before the trial. I remember thinking about the implications that both her lawyer and the defense lawyer were men as was too, the presiding judge, the nurse and the RCMP officer that had seen Lena after the rape. Would her story be different if any of these people were women?

The defense lawyer confused her by repeatedly firing questions before asking: "Wasn't it that you really wanted to have sexual intercourse?" By then Lena was so confused that she answered "Yes" – where on earth was her lawyer? This last answer clearly marked the end of the trial – I was angry, sad, disappointed, and disillusioned, but most of all overcome with a deep sense of injustice.

The jury's deliberation was short as expected. Then something happened I didn't expect and could have never imagined … once the court was declared "over", all members of the community: men, women, children, and jury members passed by Lena without acknowledging her and went to David to congratulate him. To shake the same hand that had held Lena to the bed and ripped off her panties. The same hand that had hours before the rape handed her the bottle of beer. Beer that intoxicated her so she couldn't remember the events in detail. The same hand that had violated other women on numerous occasions prior to this. The same hand that would continue to assault women. Lena remained in her seat and watched as her own mother walked up to David.

As I recall these events, tears roll down my face and I feel as helpless now as I felt at that moment. I wanted to scream loud enough for people to wake up. Wake up to what? To the reality of women's lives? To life in the margins? To an unjust world? To the silent, unheard of and unnoticed stories of aboriginal women?

It was this trial and its aftermath that marked the beginning of my strong interest in aboriginal women's lives. An interest that has grown into a passion. A passion not only to learn more about aboriginal peoples and in particular aboriginal women, but also about life and why we travel the roads we do. There are times when I have listened to stories of aboriginal women in this and other communities that I wish I had never had come and I wish I could "unlearn" – about stories of abuse, stories without mercy, without hope and kindness. Yet, it was in these same moments when I saw and heard the worst that I was inspired by the incredible resilience and strength of people. It was then that I discovered what it means to hope and to live and to see what it takes to go on. I also began to see how powerful it was to listen to stories of vulnerability and resistance … a common thread in the stories of aboriginal women.

Even though it has been several years since the trial I still wonder about it. Looking back, I continue to disagree with the perception of "social event", however I do agree with others that there was much for me to learn by attending the trial. The experience has influenced me personally and professionally and it has deeply changed how I see and engage with others. Why is the societal narrative, embodied in the justice system so loud and the voices of individuals so silent? Why is it that rape has become such a seemingly common part of aboriginal communities? Why is it that people continue to be perpetrators and victims? Why is it that these roles are commonly defined along gender lines? Why is it that mothers abandon daughters? Why is it that I feel helpless and overwhelmed by sadness? Sometimes I catch the beginning of an answer. A glimpse comes before my eyes, only to realize the complexity and ambiguity and it becomes such a daunting task to answer these questions.

It is in these moments of wondering that I long for time away, time to walk through the fields and forest of my childhood, and the sandy beaches of the lake, time to hear the sound of mosquitoes and horse flies chasing my dogs. I need to feel the heat of my husband's body as I lay beside him thinking of who I am and who are they and which part do I play in Lena's story and David's too.

As I re-visit the event I begin to see how my own story is entangled with Lena's and David's story. It is through being part of their story that I begin to awaken to my own stories, to who I am, where I have been and also where I am going.

My experiences in the north have led me to seek out aboriginal women living with HIV in the city in an attempt to understand our lives and to find answers to my questions and wonders. Like the collection of books you have in front of you, my conversations with the aboriginal women I have met over the past year have been re-collections of moments lived and imagined that can best be described as non-linear, fragmentary moments, much like visual flashes or vignettes (Kuhn, 1995). Our conversations have surrounded past, present and future events. We have shared wonders around self, family and community. Yet too, they have encircled ideas of continuity and fragmentation and the notion of autobiographical prisons, where our past bleeds into the present and our future lingers in the margins.

My love for narratives goes a long way back to a childhood filled with stories and books. There were those Sunday lunches when we gathered around the table. Lunches that would lead right into afternoon coffees, where my mother and aunt would recount their childhood, adolescent and adult life stories. These were stories we heard so many times that I lost count. Yet they always seemed new and there was always room to discover more in each story. "Becoming a writer had meant for me learning to learn from experience, often by ruminating on past events and encounters and rethinking them, getting more and more juice out of them, as they open up a spiraling cornucopia of vision. One reason it is so satisfying to return over familiar ground is that there remains so much to be discovered" (Bateson, 2000, p.229).

Listening to my aunt's and mother's stories created an awareness and appreciation in me about the connections between generations, both past and future. I began to recognize how interwoven our stories were and how much they have and continue to shape my life. However, within the intimacy of our relationships, as we gathered at the kitchen table, were stories that could never be made public. There are stories that never will be told even within the intimate connections of sisters and mothers and daughters. There are stories that remain secret and are buried deep within us.

Years have passed since those Sunday conversations, yet they still shape my understanding of family and experience strongly. They have taught me to listen to stories of unfamiliar people closely and attentively. They have influenced my understanding of the women's stories I have heard over the past year as a narrative inquirer.

Narrative inquiry is about experience and according to Clandinin and Connelly (2000) "[e]xperience happens narratively. Narrative inquiry is a form of narrative experience" (p. 19). As a narrative inquirer, I am drawn to the stories of the five aboriginal women I have been in contact with. I am drawn to their stories, because they represent a common way of telling about experiences for marginalized women. At the same time narratives also provide a channel of communication with the community as a whole (Hall, Stevens & Meleis, 1994). The underlying assumption of narratives is the belief that they provide insight into human experiences (Sandelowski, 1991).

Listening to stories, however requires an attentiveness not only to words and utterances, but also to actions, doings and happenings as they help us understand the complexity of the stories (Clandinin & Connelly, 2000). For Mishler (1986) narrative analysis emphasizes textual matters or the syntactic and semantic structure of the text, ideational matters or the referential meaning of what is said, and interpersonal matters such as the relationship between teller and listener. The study of narratives is able to reveal aspects of the social life because culture speaks through an individual's story. It is possible to examine racial oppression, power and gender inequalities that may be taken for granted by the storyteller (Riessman, 1993). Therefore, during the narrative analyses I not only have to ask 'why was this story told' but also 'why was the story told this way?' (Riessman, 1993).

The relationship of teller and listener has to be taken into account because the meaning of stories shifts as storytellers address different audiences, in varying situations and historical contexts (Cruikshank, 1998). Each story is embedded in context (Ochberg, 1994; Mishler, 1979) and without the context the words within the story become meaningless (Ayres & Poirier, 1996).

The larger socio-political processes and power relations are reflected in the stories told. Poirier and Ayres (1997) discuss a technique they term 'overreading', which is sensitivity to unspoken or indirect statements. They caution that 'overreading' has to be done with care because it is highly subjective. Similarly, the words that express our stories are often constrained by our life experiences and many stories are told within the master narrative, using the master's tools, reflecting gender, race, power and class (Romero & Stewart, 1999).

The aboriginal women are patient with me and are willing to (re)tell their stories on multiple occasions. As I listen carefully I notice how they struggle to find words for their stories and like Debra, others too speak in incomplete sentences. Our conversations are filled with long and short pauses throughout. As I listen again to the story I notice how the story changes each time, losing its sense of stability and certainty. I wonder how we will see the story once it is permanently etched in paper and ink. After all, in aboriginal cultures there is an acute awareness that oral storytelling is responsive to the context, allowing the teller and listener to resist stability and tell stories of multiple and continuous possibilities (Tafoya, 2000).

For the past twelve months the women and I have been getting together to talk about their life experiences, and for me to understand the impact an HIV positive diagnosis has on their lives. Throughout my conversations with the women it became clear that their stories had neither a beginning, middle, or end. Moments were recollected in no specific order and at times beginning in mid-sentence. And as Leen (1995) observed "stories often seem to bridge the everyday and the supernatural, or the past and the present" (p. 2) and this can be seen as an attempt to preserve cultural traditions. Yet, the stories read like journeys; the continuous forward and backward movement serves to renew and protect life. I am beginning to understand that "stories, as so many people of the First Nations have said, are a form of medicine. For most American Indian peoples, whose first language is not English, the word 'medicine' has an additional meaning beyond its connection with healing – it normally carries with it the connotation of sacredness" (Tafoya, 2000, p. 57). As one of the women pointed out

Actually, that was pretty sad, too. But I came to terms with it a long time ago, I've learned to deal with it. Before, when I told the story, I would always break down; I couldn't finish the story. But now, I can sit here and tell the whole story because I've told it so many times. It's just a human thing.

The spiritual purpose of story telling emphasizes the recognition that our conversations and encounters are part of a ceremony we share together. Embedded in the notion of ceremony is "the idea that erasing someone's story can erase the person, which crosses boundaries between narrative and human" (Leen, 1995, p.8). As I record the women's stories on paper I have to be careful, because once on paper their stories become fixed and permanent and as such risk the loss of their spiritual and healing strength. And throughout my writing I wonder if I dare go ahead given this tremendous responsibility?

However, by enabling others to read pieces of our conversation from the past few months and sharing our stories with a wider audience, the women and I recognize that "the stories move in circles, spreading out in the way of ripples from a stone cast into a pond, as they provide patterns of recognition that allow [others] to acknowledge similar experiences in [their] lives to the stories we [tell]. And finally, there are some stories that are so powerful, we don't just tell them – they tell us. Stories are a form of medicine. The only difference between medicine and poison is the dosage" (Tafoya, 2000, p. 63).

Stories not only affect us in a personal way. They can also inspire us to take action, to unglue a spirit, to cross sacred boundaries or to inspire a revolution (Leen, 1995). Most of all however, stories create a space within the margins that allows women's voices to be heard and thus give women's experiences value. Stories often tell of ordinary moments; evidence of gossip and humor, love and sexuality and self, family and community are always present. At the same time stories enable us to see human problems behind the facade of social and political ones. Stories place a human face on issues of poverty, marginalization, discrimination and stigmatization.

All too often we look at human experiences as "a social and not a personal or human problem; to think of [an African American person] is to think of statistics, slumps, rapes, injustices, remote violence; is to be confronted with an endless cataloguing of losses, gains, skirmishes; it is to feel virtuous, outraged, helpless, as though this continuing status among us were somehow analogous to disease – cancer, perhaps, or tuberculosis, which must be checked, even so it can't be cured" (Baldwin, 1955, p. 18-19). Stories then become a symbol against dehumanization.

The everyday stories of ordinary lives are so powerful and tell so much of who we are as individuals and as a society. At the same time I recognize that there are many socially constructed and pre-established stories that I am part of, sometimes willingly and sometimes resentfully. Some stories were constructed before I was conceived, even before I was born. These stories too are an important part of me.

One of the most rewarding insights for me living in a new country and working with a different culture is the awakening to these socially constructed stories. Although I had a strong awareness and inkling of these constructions before I immigrated, I realized that I had been inattentive to so much of it. I began to realize how privileged and protected I had been. I discovered stories and parts of my history that I could have never imagined.

How will the women tell their life stories? Will they talk about the roles that were constructed for them long before they were born? Will I be able to see beyond the parts and see the whole? How has their illness experience changed the whole? How much of their history is shared with their family and community? And as I carefully listened to the women's stories in search for answers I only encounter more questions and greater confusion. There were times when I wished I could listen to stories from their friends, families, and communities. Yet, after (re)listening to the women's stories, I began to see that the larger social stories are always embedded within the individual narratives and I continually wondered if I would be able to see them.

Despite the restlessness, discomfort and unease the stories evoked in me many times, our conversations are too about the pleasures of shared stories. Illustrating pleasant and unpleasant life-experiences provides an opportunity for others to understand and comprehend the diversity of human experiences. To learn through stories in the midst of our conversation allows us to make sense of our lives in a narrative way. The organic nature of narratives entails the endless possibilities of multiple ways to tell our stories, with the result that our stories will always be works-in-progress and continually under revision (Clandinin & Connelly, 2000). For me, learning about the women's lives required attentiveness to the stories they choose to live by, stories of displacement, despair, loneliness, but also stories of hope, possibility and joy.

Narratives are told thoughtfully and purposefully; they can be fluid, transformative, and intersubjective. Stories cross boundaries between the present, the past and future, between the unknown and the known, between the told and untold, between the self and others. Our identity is never fixed, and neither are our stories. The content of stories often depends on the questions asked and the personal relationship between the teller and listener (Cruikshank, 1998).

At times this narrative inquiry became part of life history research and as such allowed me to "honour moments in time [...] and, indeed, life itself is compromised of layer upon layer of interconnected moments in time" (Arielle Matiss, 2001, p. 223). It was through the process of narrative inquiry that I was able to link moments of their lives and my life together, which provided us with a sense of identity and integrity. The women all agreed to tell their stories as part of a research project, but in the midst of our time spent together the stories took on a life of their own. The women recognized this early on and pointed out that the telling of their own stories was a way to make sense of their often chaotic experiences and enabled them to make their lives more coherent. I slowly began to understand how "storied moments of time and space, and reflected upon and understood in terms of narrative unities and discontinuities" (Clandinin & Connelly, 2000, p. 17) are important therapeutic tools.

The women pressed me to help them develop their own voice and keep their identity since for them listening to their own stories was a way to encourage, nourish and sustain themselves (Howe, 1984, as cited in Cooper, 1991). In some small way I think the stories of their past and present lives became incentives for the women to look at how their lives could change and how they could live out their changed story to encompass possibilities and dreams. It seemed moments of hopes, dreams, wishes and intentions (Clandinin & Connelly, 2000) were forever emerging, evolving, and transforming a life yet to be lived.

Narrative inquiry and storytelling, both as a research method and a way to relate to others, have been marginalized by more powerful knowledge systems (Cruikshank, 1998). Yet it is personal stories that enable us to offer a unique critique of society, the current justice system, health care system and other influential institutions. It is stories that allow us to maintain a powerful subjectivity in face of an objectifying system which is dominated by western philosophical principles (Abrums, 2000).

The notion of truth and objectivity is often at the heart of western institutions and research. Current mainstream academic research generally does not accept that research is not a scientifically value-free science. Epidemiological studies often frame statistics and evoke stereotypes of marginalized peoples. These stereotypes function as political myths which justify racist policies and approaches (Abrums, 2000). Rather than accepting that "there is no 'the truth', [nor] 'a truth' – truth is not one thing or even a system. It is an increasing complexity" (Rich, 1979, p. 185). Researchers continue to simplify, codify and (mis)represent peoples' lives. Perhaps to speak the truth is to tell the most complicated of all lies (Rich, 1979).

In order to understand the complex relationship between truth and personal lives requires a closer analysis of current research findings. Statistics of HIV positive women, such as "women were more likely to be aboriginal, younger, to have had nonconsensual sex, to have IDU sexual partner, to inject heroin, to inject cocaine, to smoke crack and to require assistance injecting." (Spittal, Craib, Wood, Labitre, Li, Tyndall, O'Shaugnessy, & Schechter, 2002, p. 286) have to be placed in context. Without the historical, political and social context these statistics continue to perpetuate the stigmatization of HIV positive women. Most importantly however, is to understand how these circumstances are lived out on the personal landscape, to recognize that there is not only a multiple codependence (Mullen Sand, 1992) between the personal story and reality, but that there is yet another story, one of possibility, one of resilience.

"Any gaze is always filtered through the lenses of language, gender, social class, race, and ethnicity. There are no objective observations, only observations socially situated in the worlds of – and between- the observer and the observed. Subjects, or individuals, are seldom able to give full explanations of their actions or intentions; all they can offer are accounts, or stories, about what they did and why" (Denzin & Lincoln, 2000, p. 19). Within these personal stories the facts often become muddled and our memories unclear. Rarely is the truth and objectivity in western research and philosophical paradigms grounded in local, detailed and culturally specific events.

I ask myself, is it not with so many life experiences that as one tries to describe them, that their immense importance dissipates or is minimized or has importance to me because I know the circumstances, but not anyone else? How can I recount told stories in research text? Can I avoid losing the immense importance by revising over and over again the written text until I find the right words or does it lie within the remembering of details? Or both? Or is it that making sense of experience becomes easier the more often we speak and write about it? Or are there other ways through which we can (re)tell our stories? Pictures, strips of fragrances, pieces of cloth and colour – different shapes and symbols …

How do we learn about our own and other's existence? How do we gain insights from the multiple stories told? Perhaps insight is only reached as we place experiences, exotic and familiar, old and new, alongside each other and let them speak to each other (Bateson, 1994). The depth of our insight is not reached through the (de)personalized focus on truth and objectivity accomplished through reductionism, theory and abstractions, but through continuous re-visiting and the personal unraveling of stories and life-events.

Throughout my study I was often asked if I had accomplished 'data saturation' and if the stories of the women were 'rich' stories ... rich of what? Saturated with what? The more often I was asked these and similar questions and the longer I listened to the women's stories, the more confused I became about what saturation and richness really meant.

The theoretical issues of richness and saturation implies that the landscape of personal stories was largely unknown to those who asked the questions. The question speaks of inattentiveness to multiplicity and complexity, of their attempt to reduce personal stories to facts and truthful moments. Yet, inattention to personal landscapes is as much learned as attention on richness (Bateson, 1994).

Throughout my conversations with the women I was reminded that imagination and memory are incredible places of images, words and dreams. However, they are also spaces where people, places and things can be forgotten and easily hidden. Moreover, memory is contextual; smells, visual or tactual triggers at times reconnect us with lost memories or memories forgotten. Perhaps wakefulness (Clandinin &Connelly, 2000) relates to the ever changing story, to the story not told, and to the circumstances and the intent of the stories told, which for some is termed deception and for others embodies the depth and invisibility of personal stories.

Our conversations awoke in me the importance of our personal relationship as the tellers and the listeners of stories. Stories never happen in isolation and are never told in isolation. Sometimes they are recorded or told to an imaginable audience and sometimes the teller also becomes the listener. Sometimes stories are told to teach, to share, and sometimes because they are needed to move on and so they become therapeutic. Stories can be fictitious and imaginary. But even these are grounded in personal experience, personal history, in language and words, and limited by the words we have to express them.

There were moments when both the women and I played with the imagination and attempted to (un)tell existing stories, especially stories of their childhood and especially to create stories of change. However, it was hard to tell new stories when the pains and wounds inflicted were so deep that even our imaginary stories could not be told without (re)counting these events.

In the end the reason for us to (re)tell our stories was not so much to challenge the common truth, or perception of aboriginal women living with HIV, but rather because we recognized that "I will tell you something about stories, they aren't just entertainment. Don't be fooled. They are all we have, you see, all we have to fight off illness and death. You don't have anything, if you don't have the stories …" (Marmon Silko, 1977, p. 2). It is with this in mind that we honour our knowing and insights which stem from our personal experience and reflections.

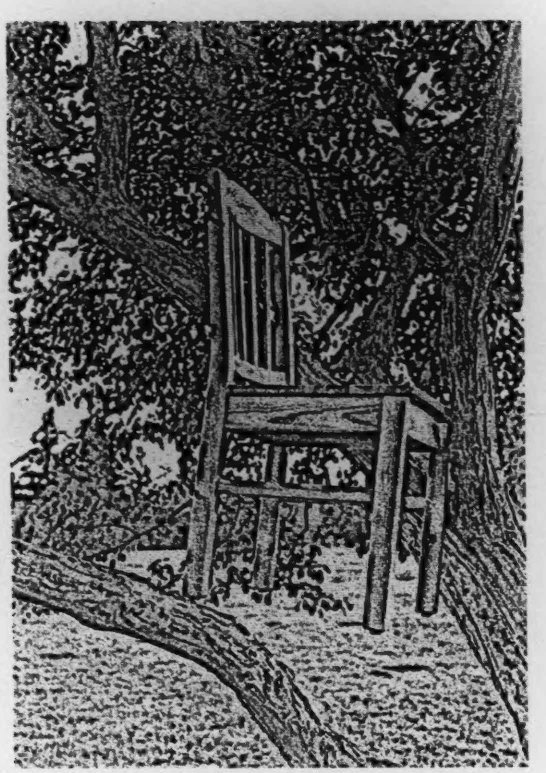
and it is in my imaginary conversations with the tree
that I begin to make sense of my life

through our shared moments
I can feel my body straightening
reaching to gently touch the green leaves

yet as my body begins to straighten
I acknowledge and remember
the smell of dirt and plants on my hands as they covered my face

kitchen table conversations

conversations in personal spaces



I had driven for hours, returning from a visit with my husband and I was filled with anticipation, unease and discomfort. This was the first time I walked up her front steps to knock on her door. As I was about to turn around and (re)think about what it really was that I came for her voice called out for me to come in, she'd be right there. I am sure she could sense my hesitation and nervousness mixed with a curiosity to see and hear more of her and about her life. I fumbled with the papers I was told I had to read and ask her to sign before we could talk about anything … to assure her I couldn't trust her and I too was not trustworthy. It was intrusive and awkward and I remember placing the consent forms far between us, where soon we would forget that we could not trust each other …

As we entered the kitchen, my nervousness slowly disappeared as amidst this unfamiliar space I began to recognize familiarity. Her table was round just like my parents' table etched with historical marks made by children and others. There was the broom sitting in a pile of dirt, waiting for the rest of the floor to be swept and cared for along with the dishes in the sink … signs of life suddenly reminded me of the reasons for my visit. For a long time we always met at the kitchen table; sometimes alone and at other times joined by children, family and friends.

With time I began to feel that I was sitting amidst life, and the uneasy feeling of standing on the other side shouting questions, making curious gazes or listening intently dissipated. Spaces where I felt continued pressure to improvise similarly dissipated. It was only with time that I become close enough to see who she was. Our conversations became conversations in personal spaces and we began to share our lives. It was in those later moments, where our conversations molded themselves into spaces where we could grow and change, that we began to see that within our personal spaces were always new stories to be discovered.

Yet amidst the told stories were also the ones that would never be told. "How can I think of untold stories? What are they? How do untold stories manifest themselves, especially in the lives of those who would tell them, and what is their significance? How might I even gain awareness of the existence of untold stories, even if I cannot know their contents specifically, and how important is it for me to do so? To what extent should I pursue untold stories? What good or harm might come from such pursuits?" (Neuman, 1997, p. 93). While wondering about (un)told, (un)disclosed and secret stories, I never lost sight of the danger of telling. Once we tell, we can never (un)tell. If we were pressured to tell (un)told stories I am sure the comfort we had gained in our relationship would be experienced as suspicious and our space would become a (dis)position for (dis)ease and distress. So we shared, each, at our own pace.

My first kitchen table conversations helped me shift from asking the right questions to being attentive to the process of research and I realize that "indigenous research is a humble and humbling activity" (Smith, 1999, p. 5). Instead of liberating or empowering others, which is fraught with danger and assumptions, our conversation about diverse and desperate times reflected the profound intensity and permanency of everyday life. It was at the kitchen table that the women began to share their deep and joyful, but also distressing experiences. *Yeah, it was pretty upsetting for us there, pretty stressful. That was harder than his tests. It was harder than his test because at least I had some kind of an idea of what to expect, but with this, it was just unreal.*

As Bound and Walker (1998) remind me "[t]he boundary between professional space and private space is not fixed, but needs to be clarified in any given setting in order to avoid a particular version of what Habermas (1987) referred to as 'colonization of the life-world that is the intrusion of institutions – work, profession, educational institutions – into the domain that has been regarded as personal and in the hands of the individual to share" (p. 202). And so my curiosity had to be balanced with ever-present aspects of intrusiveness, colonization, and invasion. How could I reach this balance? How can I sit at her kitchen table without unease and distress? What can I do to shift this existing power imbalance? How can I enter personal spaces? For me these became important questions; to achieve a dialogue based on equal relationship, respect and understanding was significant in avoiding the intrusive nature of research. Most of all however, it was a recognition that "[l]ife history researchers step into lives only to retreat after a time; yet, those examined lives live on both within and without the researcher's experience" (Cole & Knowles, 2001, p. viii). And so I tried to leave marks of caring, trust, and connectedness etched into the kitchen tables behind.

From the onset of my relationships with the aboriginal women I was more intrigued by ordinary people and ordinary life stories, because I strongly believe that much of who we are is shaped by personal and everyday experiences. Like Gullestaed (1996) "I hope to show that 'ordinary people' relate in creative and complex ways to structural conditions and to social categories, labels, and concepts associated with such conditions" (p. 3). It is within cultural and social contexts and everyday life that the women and I were able to locate our own voice and discover what it means to be aboriginal, non-aboriginal, or to live with an HIV positive diagnosis.

Within the everyday experiences of the women it became clear that their HIV positive diagnoses was not the most pressing matter in their lives. Life at home goes on and unfolds in multiple and diverse ways despite the positive diagnosis. Their desires, passions and life are not taken away because of their HIV positive status. In their everyday lives the women continue to care passionately about their children, lovers and family members.

As my colleagues listened to the stories of aboriginal women, they questioned my interest in the countless, seemingly mundane, everyday experiences. They warned me not to waste my energy but I know better and invest more energy in order to create difference, multiplicity, space, silences, complexity, and creativity all of which is present in our wonders of everyday life.

And so I began slowly to interweave fragments of my own story with fragments of stories of these aboriginal women. I am so glad I have become increasingly attentive to stories again and I am begin to tell and write them again slowly – it is difficult and hard work. Through our conversations I begin to see how my own life has been influenced and has changed by listening and thinking about their stories. How will our conversations affect the women?

Perhaps our changing stories are part of "[l]earning to savor the vertigo of doing without answers or making shift and making do with fragmentary ones opens up the pleasures of recognizing and playing with pattern, finding coherence within complexity, sharing within multiplicity. Improvisation and new learning are no private process; they are shared with others at every age" (Bateson, 1994, pp. 7-8).

Narratives are told thoughtfully and purposefully and are usually situated within everyday life (Cruikshank, 1998). Like personal identities, narratives are never fixed; they are fluid, transformative and cross multiple boundaries. There is a continuous shift between the present, the past and the future, between the known and the unknown, between the told and untold, and between the self and others. Understanding this complexity and the ability to recognize these shifting stories is crucial when learning from everyday life, because inherent is the recognition that each human journey is different.

When the women speak of their experiences of living with HIV, they speak of multiple and diverse ways of making sense. However, many of their stories are oriented towards the present and almost always have spiritual and emotional components. As a consequence of their illness the women have gained new insights and increased their understanding of self (Ezzy, 2000). In the amidst of sharing their stories with me, I recognize that the women have engaged in multiple internal dialogues to make sense of their HIV positive diagnosis. From the despair, loneliness and desperation that arose from the first diagnosis some women have moved on to contemplation and a recognition of possibilities and dreams. At times our conversations of everyday wonders were concerning oppression and exploitation that seems to be ever present in these aboriginal women's everyday life. At other times, our conversations shift from taking medications and their lack of confidence in treatment, to talking about their children. Yet, in almost all our conversations we talk about dreams, possibilities and the wonders of everyday lives.

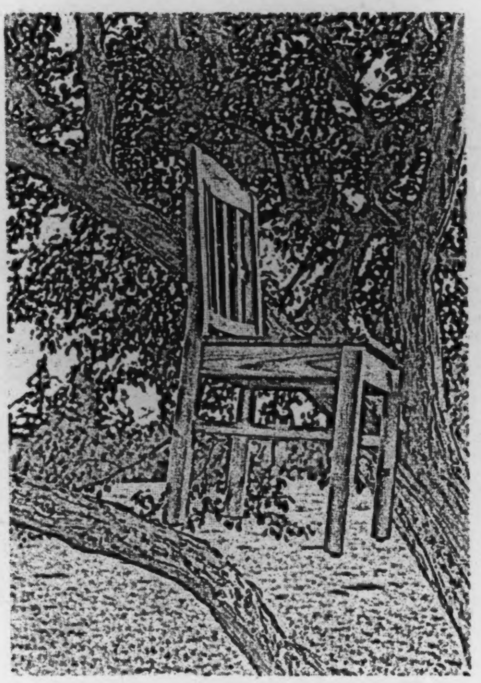
remembering moments long ago

across oceans ~ between mountains

amongst trees and kitchen tables where

conversations in personal spaces

deepen our lives

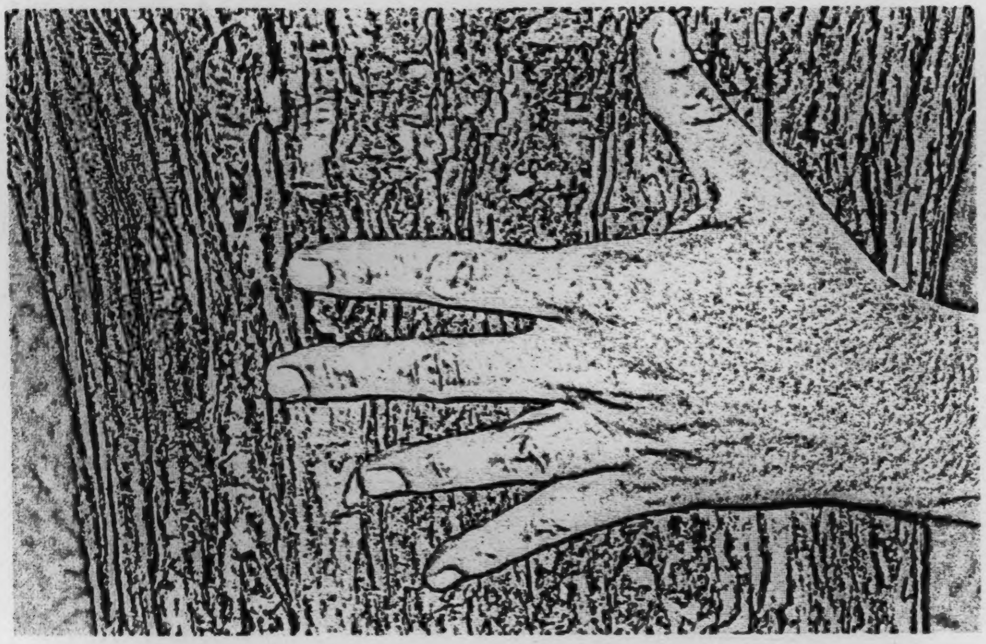


research as relationships

I want to stay open

explore and push boundaries

find meaningful ways of relating



Memories return to the times I was welcomed into the homes of aboriginal women in the Northwest Territories; of times where we shared tea, laughter and stories. A time where I felt I had begun to find familiarity in the unfamiliar. Back then I saw myself as a stranger in relation to these women. Not an outsider, a stranger – unfamiliar with their experiences and life. Even now as I connect with aboriginal women in the city I feel as though I am seeing through the eyes of a stranger exploring unfamiliar land. At the same time I am also beginning to see where I do connect with their stories, stories of being a woman, living on the margins, amidst different cultures. And so I need to be attentive to the moments where my story has already intertwined with their stories. To reflect on these moments means becoming more familiar not only with their story, but also with my own. "In becoming adults we are encouraged to put the child behind us, to disbelieve our own stories and our own childhoods [...] the value of autobiography is that it creates forms of embodied knowledge in which the (adult) self and the (child) other can rediscover and reaffirm their connectedness" (Behar, 1996, p. 134-135).

Becoming familiar meant acknowledging that the aboriginal women and I were strangers, and that our beginning relationship was marked by discomfort and unease, but also surprise (Bateson, 1994). The beginning was difficult and it was only through continuous asking, seeking, sharing, celebrating and rejoicing, that our relationship lost its strangeness. Moreover, I could see that only through the compassion and strength of the women was I able to become familiar with their lives. The women made me see. The investment of energy into our relationship pointed to the women's inner strength and their belief that establishing relationships still remained worthwhile, despite all the tragedies their lives had entailed. Our relationship brought life to the stories, life in its unfolding nature.

Becoming familiar also meant to arrive in new places, foreign places. "In each place that we settled, we came to know ourselves more fully through our relationships with the places where we lived" (Cajete, 2000, p. 183). Coming to know ourselves more fully led not only to the development of mutual trust, but also to increasingly trust our own abilities. The women and I arrived in places where intimacy and strangeness formed a new relationship, composed lives (Bateson, 2000), and provided distant hopes of friendship.

However, becoming familiar was not without its challenges. As a researcher I am bound by the obligations and rules of the academic institution. Rules that confined the relationship from the outset. Ensuring written informed consent, although a mechanism for protecting the participants in research studies, set up huge barriers and framed the research relationship immediately. It emphasized power differentials between the participants and myself and issues of (mis)trust surface. I was often distressed and found it difficult to explain that it was not me who mistrusted them, but rather an academic body who was afraid to encounter legal problems and did not trust researchers to take responsibility for their actions. One of the participants commented *Oh, I should have expected that*. Informed consent and other ethical research rules are "– a conscience – to remind us of our accountability and position. Stripping us of our illusions of friendship and reciprocity, it made working the hyphen even more difficult" (Fine, Weis, Weseen, &Wong, 2000, pp. 113-114). As a result of these experiences I was pressed to think through issues of power, obligations and responsibilities. I realized that I needed to be creative and flexible to adapt or change the existing rules; rules that were after all produced in a different place for a different purpose by someone unfamiliar with our relationship (Gottschalk, 1998).

Respecting aboriginal peoples' long and rich history of oral traditions and story telling, pressed me to create spaces within which the mutual sharing of stories provided a space for exploration, strength, creativity and possibility. "In oral cultures, storytelling maintains and preserves traditions. It takes listeners [and tellers] on a journey and a renewal of life" (Leen, 1995, p.1).

Throughout our conversations I encouraged the women to use their own words and talk about what was important to them avoiding interruptions as much as possible. Enabling the women to tell their story without the language constraints inherent in questionnaires and structured interviews was an empowering experience, largely because it overcomes invisibility and silencing with which women are so familiar (Hall, Stevens, & Meleis, 1994).

However, eliciting accounts of their experiences was not simply a matter of encouraging the women to speak, because "most members of society learn to interpret their experiences in terms of the dominant language and meanings; thus, women themselves (researchers included) often have trouble seeing and talking clearly about their experiences" (Devault, 1990, p. 98). It was also critical to create an environment in which both the women and I felt comfortable and safe to explore who we are. The reciprocity of our relationship became essential for true intimacy (Oakley, 1981) and implied 'give and take' and a mutual negotiation of meaning and power. Our conversations perhaps can best be described as exchanges and dialogues (Oakley, 1981), where I honoured the women's ways of knowing and their knowledge, grounded in their experience (Wang & Burris, 1994). Do we know our own lives well enough to tell and if we can't tell, can we let others tell? Do strangers understand our intimate language? Do we speak the same language?

Throughout our conversations I wondered how I heard and interpreted the women's story. At the same time I was reminded by my colleagues to be aware of how these women hear my stories and as well as their stories re-told, as narrative inquiry is reciprocal and relational. As I began to be more and more involved I was warned to not get drawn in, to avoid ethical dilemmas. Yet, for me not being fully engaged posed problems and dilemmas of equal magnitude and concerns of distance and separation surfaced. After all, it was closeness, identity, voice, reciprocity and trust I was seeking in these new spaces. “The authenticity of the researcher and his or her ability to become engaged in the research process as a whole person … involves an ongoing investigation of one’s own experiences, intentions, expectations, and prejudices in the context of each research endeavor” (Donnell Connors, 1988, p. 34). The aboriginal women and I engaged in multiple conversations and over time our conversations became a joint responsibility. And it was in this collaborative process that I became more aware of what we do to ourselves and to others as we engage in research.

Our conversations in shared personal spaces can be characterized by negotiation, collaboration and participation. These are principles that reflect the influence of Clandinin and Connelly (1988) who address issues of collaborative research, the ethics of participation and the concept of negotiation. As collaborative researchers our efforts became a collective process with mutual responsibilities to listen and be attentive to our told and (re)told stories.

Much of our negotiation evolved around the directions our conversations would take. Experience is always messy, stories change and evolve and as a result, new directions have to be negotiated. Throughout this research a thought recurred many times: Maybe this thesis will not be about aboriginal women living with HIV/AIDS. What would I do when this happens? (Re)negotiate, collaborate and participate in another story? Will the collection of field text become overwhelming? Although the field text did in fact become overwhelming, and as our conversations continued to be diverse, I never lost sight that I wanted this to be a collective experience, to engage in a co-operative search, to negotiate the questions and the ways in which we can re-tell our conversations as women from different backgrounds and experiences. Negotiating which stories and pictures would become accessible to the public eye became important as well and shaped our conversations. It was through the continuous collaboration and negotiation that the women and I felt we each had a voice with which to tell our story (Connelly & Clandinin, 1990). Gaining voice for some of the women meant feeling good about themselves: *I could be having a really shitty week or something, and then I see you and then we go out or whatever, and then I just feel good about myself again.*

However, our conversations were not without structure. Four is an important number in aboriginal culture. It is reflected in the medicine wheel and the sacred hoop. The wheel encompasses the four directions, which represent the cycles of the season or the life cycles, as well as the four aspects of human life. And as we began to tell our stories we were attentive to the four directions: honouring our child, youth and adulthood and anticipating our future. The aboriginal women's journey of living with HIV also pointed to some of the four directions, as described by Weiser (1998).

Much like a child, the direction of the east, all the women were initially unaware of their HIV positive status. The asymptomatic stage, pointing in the direction of the south, or adolescent years, was the point at which the women tested positive for HIV. This time was difficult for all of them and marked by despair. The symptomatic stage, points to the west and is characterized by reflection, as if entering adulthood the women make sense of their diagnosis and take responsibility. The northern direction, or AIDS stage, leads people to accept the inevitable and to find resolution and peace. It is important however to acknowledge that one does not necessarily travel through all the directions in a linear way, or even experience all the stages.

As a narrative inquirer I also was aware of four other directions that Clandinin and Connelly (1994) speak about; the directions of inward and outward, backward and forward. "By inward we mean the internal conditions of feelings, hopes, aesthetic reactions, moral dispositions, and so on. By outward we mean existential conditions, that is the environment … by forward and backward we are referring to temporality, past, present, and future. To experience an experience is to experience it simultaneously in these four ways and to ask questions pointing each way" (Clandinin & Connelly, 1994, p. 417).

As the women and I moved from field text to research text we explored how we could re-tell our collaborative story. For the women it was of immense importance to maintain the integrity and cohesiveness of their story, to recount their entire story and to maintain their identity. To tell about their life history was a way to integrate HIV as a part of their life story, particularly to show that they tried hard to resist being defined by their illness alone.

I was continually amazed at the openness and the depth to which some of the women went in telling their story. It was as if they discovered the richness of their lives for the first time as we re-visited the villages, towns and settlements of their childhood and youth on several occasions. And as we began to re-read the transcripts I tried hard not to make judgments and to stay as close as possible to the woman's realities (Abrums, 2000). Throughout all my encounters with the women I never just saw them as a high risk or vulnerable group, because their lives were much more rich, diverse and complex than a label could imply. There were times when our conversations lasted for hours spending as much time as we could together, to talk and make sense of our lives. We often returned from our visits feeling weary, yet we had only just begun to understand each other.

continuity

Although we are now in the final stages of (re)thinking and writing about our conversations, our relationships and the close bonds we have formed continue, and we carry on listening to familiar stories. As the women (re)read and (re)look at the photographs of their books new stories begin to emerge and new possibilities are revealed. Possibilities that were not available to them before this research. Like other researchers working with aboriginal peoples I recognize that our relationships extend far beyond our research relationship and include family and social networks as well as service providers (Smith, 1999). Closure is an ongoing process and has became a part of our conversations. Nevertheless we realize that the friendships we have formed continue to live on in our lives and in our imagination.

The women are slowly beginning to recognize the multiple layers of their personal narratives and life histories and see the deep connections amongst them. And so as we read their stories, the pleasure and joy in having created a coherent way to tell others about their lives, moves us from being powerless to a place of commitment, activism and change. The spirit in documenting their lives has changed who I am and like

Bach I too attend to the words of May (1980, as cited in Bach, 1998) about covenantal ethics "at the heart of a covenant is an exchange of promises, an agreement that shapes the future between two parties. This promise grows … and acknowledges the other … It emphasizes gratitude, fidelity, even devotion, and care" (p. 65). I am aware that gratitude, fidelity, devotion and care are mutual and that in our conversations, the women have tried hard to make sense of who I am and why we meet to talk about our lives.

Many of our conversations were audio recorded and transcribed to create a textual database. The transcripts reflect both the content and the structure of speech. Verbatim transcripts with strict notations of features of talk such as pauses, repetitions, false starts and asides are essential (Sandelowski, 1991) because they can provide clues to emotions and meaning (Paget, 1983).

The majority of the women and I have read the transcript of our conversations several times over an extended time frame to grasp its full content (Emden, 1998) and to be able to identify the multiple layers of data. There were many times I felt anxious and uncomfortable, wondering about their responses as they saw the printed words of the transcripts, but more so when we finally read the story of their lives we had composed. And just like their story, their reactions too were different. Sometimes resulting in more conversations, sometimes in silence, where we shared tears of sadness and relief to have accomplished this work. Often, we could not read the book in one sitting but rather had to pace ourselves. It was as if we had to get reacquainted with our own lives as written in text.

As the women and I validated the emotional, intellectual, physical and spiritual knowledge we had gained through our conversations, I struggled with letting the data speak for itself, avoiding the heavy overlay of theory, such as marginalization and the risk of dissecting their stories into pieces. We were pressed to find ways to document our lives without violating our reality (Acker, Barry & Essewald, 1983). Furthermore, how do we maintain the integrity of their narratives and not be dismissed by the academic community, by service providers and policy makers? At the same time, we were aware and acknowledged that whatever we wrote could be used for political purposes in ways we have little control over. I wondered if the overlay of theories and ideas would protect us yet make it difficult for others to understand. At the same time I was more afraid that it would make it so easy to lose sight of the complexity of women's lives (Lather, 1986).

The continuous asking of questions and the constant re-turning to our conversations led me to believe that to share our conversations without the overlay of theories, was to reaffirm the value of our life experiences and a way to share the complexity of our lives with strangers. Most of all, this format is a response to the women's desires. The motivation for the aboriginal women to engage in this project was and is, to share their stories, so others can learn - particularly hoping that other aboriginal women will learn from someone just like them, in essence their peers. The discourse community we seek is one of others like us, who make sense of their lives through storied moments, shared amongst strangers who slowly begin to became familiar.

Kiyânaw

you & I,

you & we

we

As we co-created and co-authored the texts that would tell about their lives, our conversations and the hardships and tragedies the women had experienced gained not only new meaning, but saved their experiences from becoming meaningless (Gadow, 1999). As the women and I began to recognize the power in their stories, I began to think about multiple ethical issues.

Throughout our construction of the text I became increasingly concerned about my ability to ensure and protect their anonymity and the anonymity of their family and community. I was concerned about being unable to provide a safe space. Yet, how could I deny them an identity? We had multiple conversations about the use of their real names and photographs. I asked the women to talk with their families and communities and the responses were often: *Why? Don't be ashamed. Use your own name, don't hide your face.*

In our conversations I remembered that "for a life to maintain another life, the touch has to be infinitely delicate: precise, attentive, and swift, so as to not pull, track, rush, crush, or smother" (Minh-ha, 1989, p. 38) and so I respected the women's desires. I continued to encourage the women to pose questions and to voice their desires. After all, "ethics is about questioning […] which requires openness, deliberation, self-reflection, uncertainty and contemplation" (Bergum, 1999, p. 167).

Though our conversations around the co-construction and co-authoring of the text I became more attentive to potential readers and listeners of our stories. It became important to us as we wrote, to leave many white spaces and large margins to try and invite the reader and viewer into a dialogue, to extend our conversations beyond the printed words and pictures. We have deliberately left room for the telling of another collaborative story, grounded in the experiences of the reader and listener. "Indigenous storytelling assumes a relationship between speaker and listener. A listener becomes knowledgeable by hearing successive tellings of stories and may mull over, reinterpret, and absorb different meanings with each hearing" (Cruikshank, 1998, p. 144).

Inviting the reader into a dialogue and to respond to the stories told also creates a responsibility in the reader to contemplate how their own stories connect to the stories of these women, and which part they play in the women's story. No story can truly ever be told in its entirety and thus readers may contemplate possible past, present and future events and happenings of the story told (Schulz, 1997). As we allow others to become part of our story we make ourselves vulnerable to their interpretations of our lives.

The process of writing takes so long and much of it is not spent sitting and typing and reshaping; rather it is spent trying to make sense. To make sense of what I read, but also to make sense of a different way of telling my story. I am struggling to place myself and to find a way of expressing who I am in my own research. To what degree do I want to see 'me' reflected in my research writings? Do I want to make myself vulnerable, as I do not know who will read this work and how they will interpret it? Yet, I am drawn to narrative inquiry because I want to read and learn and hear from and about the 'I' of others. How can I ask others to tell, but refuse to tell of myself and of our relationship? I am not afraid to make parts of my private life public, but I am afraid of the other person who interprets my private life from the limited publicly available information they have. They do not see all that surrounds me, shapes me and the parts of me I have not shared or those shared only with close friends.

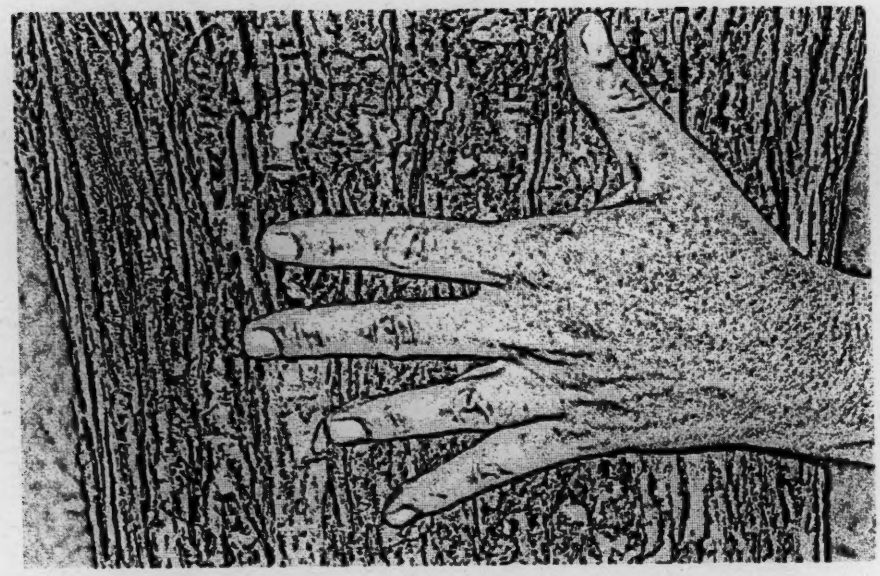
However, since narrative inquiry is relational in nature it is vital for the researcher to not only listen to the stories of the participants, but to "re-look" and examine their own life stories and experiences and evaluate how the research affects and changes the researcher. Each story, including the story of the researcher, is embedded in context and nested within a relationship. "We learn that we, too, needed to tell our stories. Scribes we were not; story tellers and story livers we were. And in our story telling, the stories of our participants merged with our own to create new stories, ones that have been labelled collaborative stories. [...] a mutually constructed story created out of the lives of both researcher and participant" (Connelly & Clandinin, 1990, p.12). Perhaps without the close relationships we have, we are unable to make sense of our life experiences. Therefore, raising questions about our relationships means to raise questions about ourselves. In an attempt to answer these questions, we need to became increasingly self-reflective, open to uncertainty and contemplation.

Looking at our relationships and our conversations means to gain a deeper level of understanding, to enter a new space one in which we feel comfortable looking at ourselves. As I begin to question who I am in this research endeavour, I am pressed to begin a dialogue between the multiple 'I's within me, pressed to begin a polyphonic dialogue, one that celebrates mystery and creativity. I begin slowly, and with hesitation, a process of self-reflection. Only with time do I realize that I am nourished and encouraged by my own internal dialogue; I begin to be attentive to my own feelings, attitudes and values. I begin to see where I have been helpful to the aboriginal women and where I have reinforced their position as marginalized and voiceless women. Who we are always shapes our research. Moreover, it is when we become engaged, not disengaged and we move beyond observations that research becomes a life-experience that is decentering of self (Bergum, 1999).

While reflecting upon who I am I begin to see the multiple ways my personal life has been shaped by my encounters, conversations, interactions and relationships with the aboriginal women. Discovering myself has brought with it tensions and contradictions and forced me to look, (re)look and (re)think my position amidst relationships and encounters. (Re)looking has pushed me to (re)evaluate my ethical understanding and responsibilities amongst my relationships with my participants. Despite challenges and tensions my reflections have brought forward n hidden subtext of scholarly works but because it offers, in the midst of colorless abstraction and obfuscating jargon, the surprise of a recognizable person" (p. 456).

My relationships with the aboriginal women are continuously evolving and shifting. As I gain glimpses of who I am, I begin to see that "these intensive relationships require serious consideration of who we are as researchers in the stories of participants, for when we become characters in their stories, we change their stories" (Clandinin & Connelly, 1994, p. 422).

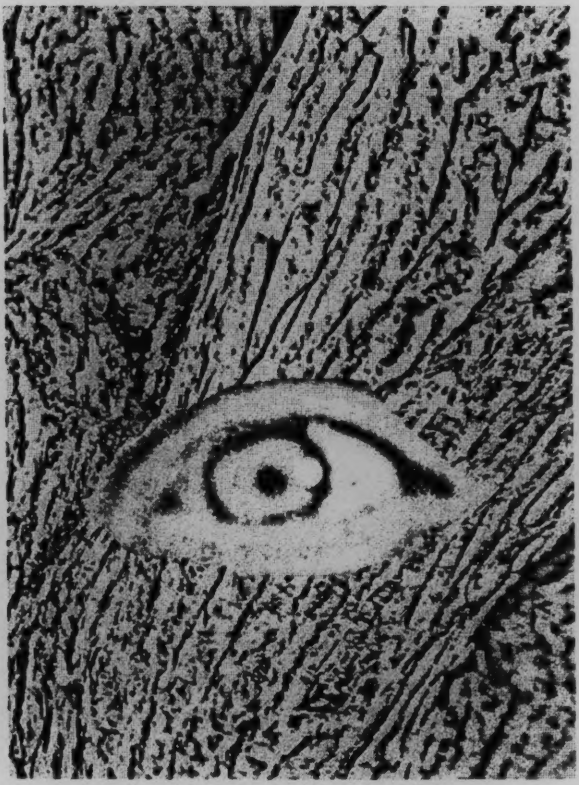
“The desire to enter into the world around you and having no idea how to do it, the fear of observing too coldly or too distractedly or too raggedly, the rage of cowardice, the insight that is always arriving late, as defiant hindsight, a sense of the utter uselessness of writing anything and yet the burning desire to write something, are the stopping places along the way. At the end of the voyage, if you are lucky, you catch a glimpse of a lighthouse, and you are grateful. Life, after all, is bountiful” (Behar, 1996, p. 3).



moments of staring

Tôhkâpi

open one's eyes



i get to take pictures of everything i love

In between our conversations the women utilized disposable print film cameras to document their everyday lives visually. Each participant chose what, how, when and where to take photographs and then later, choose the photographs they wanted to share with me. The photographs the women shared with me reflected the women's own experiences, their intimate cultural and personal knowledge. Without rules and guidelines the photographs were often taken with spontaneity and from the heart, revealing their wonders of everyday life. The photographs were varied; some taken by themselves, others taken by lovers, children, family members or friends. Sometimes it was difficult to decipher who took the picture; even the women could not remember at times.

Taking, viewing and keeping subjective photographs was also a way to resist assumptions, and the photographs inspired many of the stories told. As Weiser (1975) and Spence (1995) have shown that photographs are a verb, allowing for the continued (re)telling and (re)visioning of existing stories. As a verb the photographs become an abstract representation of an interior movement (Eisenberg, 1998), and thus amongst multiple commitments, decisions and obligations, the photographs encoded feelings and insights. "If I allow myself to freely associate around the theme of personal illness, a range of images flows past my mind's eye. Initially all are negative: images of pain, fear, silence, suffering, deprivation, unhappiness and loss through death – memories mostly of people I love, whom I remember as 'victims'" (Spence, 1990, p.75). Most of the photographs the women shared with me were only indirectly about their illness, and the majority of images were not negative. Indeed many of the pictures were of joyful moments.

The women were excited about the making of photographs and some of the women would ask me almost weekly for more disposable cameras. Creating the opportunity for creative expression enlarged both the participant's and my own ability to communicate in a different voice, with a different medium. We were all learners in this.

Tammy never seemed to have enough frames left on her camera. The way she took photographs reminded me of the way she lived her life, everything with intensity. When Tammy described the reasons she had a camera to others she would say *so I can take pictures of everything I love*. Almost all of Tammy's photographs reflected her sense of family and her wanting to belong so desperately. The photographs were a way to recognize and affirm the directions of her present and past life. Tammy's photographs continuously drew me in, confused and fascinated me. Most of all however, her photographs constantly pressed me to look at my own life and awakened me to my issues with family roots, separation, loss and death.

However, Tammy not only restricted her collection of photographs to the ones she had taken with the camera I had provided, but began to bring out boxes of family photographs and photo albums. And so the photographs we looked at together, not only represented ordinary moments and current minute details of life, but also past significant people and events in her life.

After several of our conversations Tammy began to arrange her photographs in a collage: a collage she entitled "*Family Love*". She proudly displayed this collage in her living room, visible to everyone's eye and a constant reminder of what was most important in her life. Photographs displayed on walls are "fundamentally different from photo albums. Rather than shutting images away, where they could be seen only upon request, the walls were a public announcement of the primacy of the image, the joy of image making. To enter black homes in my childhood was to enter a world that valued the visual, that asserted our collective will to participate in a noninstitutional curatorial process" (hooks, 1995, p.61)

There were others however, who had no family or individual photographs of the time they grew up. For some of the women, the non-existence of family photos from the past was a reminder of a life that never was; the lack of photographs spoke of the lack of familial affection and a feeling of isolation and loneliness. Yet, it could also be representative of very low self-image, or a fear of being seen, an image of themselves that would possibly be inescapable (Berman, 1993).

Several of the women had little difficulty thinking about which photographs to take while others contemplated the process for months. However, all of them did take pictures, each at their own pace. All of the women took photographs of places, spaces, and people. A person unfamiliar to them would normally not see these photographs, yet at the same time they were events and feelings that needed to be seen and heard, photographs depicted the richness of their relationships with others and with life.

Reflecting upon our relationships over the past months I begin to see how the photographs helped us build trust and intimacy over a very short time period. There were many times when we were absorbed in family albums, times at which I began to meet their parents, siblings, children, and other extended family. But most of all it was these were times where I began to see the women and share their life experiences in ways impossible through words alone. The photographs had the power to engage us in the continuity of life; life disrupted by an HIV positive diagnosis, life embodied in the existence of old and new photographs.

The photographs the women took were often self portraits representing positive images of themselves and those who were important to them. The statement these images made often stood in contrast to the stories they told. It was as if the photographs provided them with a space to resist the told stories (Smith, 1998), particularly to challenge the commonly told story of aboriginal women living with HIV as substance users, prostitutes and people with chaotic childhoods. "The portraits that populate family photograph albums are perhaps our most telling cultural images. Too common, too formulaic, too intimate in their casualness, their seriousness, their repetition of poses and props and forms, they tell us things about ourselves, about our families, about our places in the cultures we in habit, and even about ability to question and resist those frames" (Smith, 1998, p. 181).

At other times photographs provide continuity, even if relationships were shattered and parents and children or siblings were separated (Hirsch, 1997). Women whose children had been apprehended or removed for periods of time treasured photographs or newspaper clippings of their children. These photographs helped them form and sustain their maternal bond; to find new ways of mothering. The women often examined and talked about these photographs in great depth as it was a way to help them make sense of the loss and separation. So often the content of the photographs was sensitive, bringing forth deep issues of their mother-child relationship, family relationships and their own childhoods. For some of the women it brought forth reminders of how life follows so unintentionally circular patterns and repeats itself unintentionally (Berman, 1993). I learned quickly how powerful photographs could be, how the connection with images in the photographs can evoke deep and buried feelings, and how looking and re-looking at an image can be a trigger to deep emotional, spiritual, physical and psychological scars.

I become more and more aware that people do not take, collect or store photographs that do not matter in some ways (Weiser, 1990). Throughout the past year I began to look at my own family photographs and the photographs I had been placing carefully and sometimes not so carefully in boxes or albums. I became more attentive to my personal motives of keeping photographs, and I became less anxious about taking photographs and having photographs taken of me. Suddenly I began to realize photographs can carry in them the image of life; they are pieces of our spirit, photographs that demand our attention to the stories that they tell and conceal.

At times the women shared their very private photographs with me, the ones their lovers would carry in their wallets, or the ones that were carefully placed at their bedside. These were photographs that spoke of love and desire and at times of loss and disappointment. They represented "[p]hotographs, as the only material traces of an irrecoverable past, [which] derive their power and their important cultural role from their embeddedness in the fundamental rites of family life" (Hirsch, 1997, p. 5). The photographs affirmed the physical presence of others in their lives. I came to understand that there are certain things people leave behind to ensure that others remember them, a sign that the relationship mattered to them. Several of the women entrusted me with photographs of themselves, by which I could remember them and our relationship. And then there are the photographs the women and I entrust you the reader and viewer with, as a way to connect and tell a different story.

Some of the photographs that we share with the reader are embedded within text, these photographs are placed in close context to the text and are surrounded by interpretive words, or the photographs are placed in the context in which they were first discussed in our conversation. At other times the photographs are purposely left in an ambiguous format, with little text in order to stimulate suggestions and ideas, or to tell a contrasting story (Said, 2000). The photographs allowed us to create a multi-textured, multi-layered, and multi-dimensional story. All the photographs included are intended to make the reader look at their own history, to moment's situated in their past, to reflect on family moments, on shared loved and understanding, or to reflect on difficult times (Hirsch, 1999).

The inadequacy of language has always struck me, not only because English is my second language, but because many times have the words "I am not sure I can talk about this" passed my lips. There are other layers and sometimes secret layers to the stories I tell that are reflected in particular colours, graphic symbols, and iconic images. I often wondered how do we understand these layers? Do these symbols and images represent the languages of the (un)sayable?

At times there are images in my mind alone, landscapes of my childhood, places I once was so familiar with. Indeed these landscape images now become impossible to detach from my childhood and adolescent stories. "Stories cannot be separated from geographical locations, from actual physical places within the land. [...] And the stories are so much part of these places that it is almost impossible for future generations to lose the stories because there are so many imposing geological elements" (Hindman, 1993, p.3). Everything is connected to landscapes, the hills, the rivers, the lakes and trails – our stories are interwoven and placed within this landscape. The landscape has shaped how I think and (re)search as an immigrant women becoming familiar with a new landscape.

It is recognized that photographs can function both as starting and reference points for discussing the unknown and the familiar (Collier & Collier, 1986). Photographs are a way to remember the autobiographical self, to (re)awaken the self (Rugg, 1997). A comparison between verbal interviews and interviews using photographs indicate that participants exhibited greater interest and gave more information during photographic interviews (Touliatos & Compton, 1993). Increased sharing of information may be due to the fact that during photographic interviews photographs become a third party. The women and I become co-participants and our focus is shifted away from us to the photograph (Smith Percy, 1994). After all, it is safer to ask about a person in a photograph than to ask the person directly (Weiser, 1988).

Narrative visual theory attempts to explore the relationship between people's lives and the surrounding world (Wagner, 1979). Social science researchers frequently utilize this method, which requires the photographer to be reflexive and introspective. Inviting women to take photographs actively engages the women in the data collection and allows them to take ownership of the research process, and shifts the power imbalance.

The limitations of the camera are fundamentally the limitations of those who use them (Collier & Collier, 1986). All photographs are subject to the personal values and the incomplete observations of the photographer. To overcome this limitation it has become more common to use a technique called photo elicitation, first described by Collier in 1967. Photo elicitation is a process whereby the photographs are taken back to the participants. The individual within the picture or related to the pictured world is then asked to speak about the re-presented experiences with a reflective depth. It is important however to remember that the "memories evoked by a photo do not simply spring out of the image itself, but are generated in a network, an intertext, of discourses that shift between past and present, spectator and image, and between all these and cultural contexts, historical moments" (Kuhn, 1995, p. 12).

Photographs are an interpretation of the world and it must be emphasized that photographs are not unambiguous records of reality. The sense we make of them depends upon cultural assumptions, personal knowledge and the context in which the photograph is presented (Ball & Smith, 1992). Photographs are snapshots of seconds of reality and they may not show "the richness of the situation because they stop the action and record only one piece of total reality" (Bruderle & Valiga, 1994, p. 140). Photographs in themselves yield limited information; they are isolated moments and it is the context that provides meaning. Is the moment that the picture was taken truly representative of what the women intended to say?

A photograph may also be seen as an illusion, because no one is ever able to re-represent the fully lived moment in a photograph; therefore photographs become illusionary realities (Weiser, 2001). From a postmodern perspective photographs are context specific and their meaning depends on who is viewing the photograph and the circumstances during which the photograph is viewed.

As my eyes return to the photographs on my wall I recall the events surrounding the time each picture was taken. The pictures prompt me to (re)count another story; they become triggers to my memory. Photographs invite reflection and open expressions of the human experience revealing information that other methods might not. Photo-biographical work in particular can be a cross-cultural communication bridge (Weiser, 1988) and can be a beginning for telling stories.

Like writing, photography is a way of finding out about ourselves in that photographs allow us to create a visual story. Photographs are a way of telling and seeing our own story. And when I look back at the beginning of my relationships with the women it is clear that we see and look before we begin to talk. When we now begin our conversations about their lives, we often gather up the snapshots and lay them out to see what narratives the images tell, in order "to turn experience itself into a way of seeing" (Sonntag, 1989, p. 24). We continuously change and (re)arrange the story and the relationship between what we see and what we know appears forever unsettled (Berger, 1977). Our spoken words cannot simply be separated from the stories or vice versa. They each enhance our understanding in a different way (Knorr, 1996). Photographs provide evidence that our lives are forever changing.

Looking at the photographs on my wall I catch myself reflecting upon the past, the present and the future, beginning to (re)tell my story and to see anew. Photographs are like a mirror with a memory; they provide visual images that act as a bridge to reality (Adams, 1948). Photographs are symbolic representations that provide access to individual's experiences and perceptions of the world. Photographs can tell of life moments, create a snapshot of the world, serve as historical documentation, or create permanent artifacts. Photographs can show both concrete and abstract images; images that are unique and cannot be recreated. But there are times when these images live only in our imagination and become pictures in our mind. Photographs provide a visual language which "uses the universe as a metaphor for the invisible, a communication between the world and the spirit, a mystical relationship" (Rivet, as cited in Poitras & Rivet, 1999, p. 40).

Photographs add layers to our stories and often make our relationship with language more complex (Lowry, 1999). They provide us with visual insights and illuminate the self. "How one chooses what to include in a snapshot, when to shoot, which to keep, and why; these are all statements of self (and values), of personal uniqueness and cultural context, and they stand for us not only to ourselves but as communications to others who view them, even if they speak a different language" (Weiser, 1988, p. 254).

As the women and I engage in visual reflexivity both behind and in front of the camera we are conscious that our photographs are only one version of our reality, that the photographs speak to how we choose to represent ourselves at that given moment. Simultaneously we are conscious that the viewer or observer create their own meaning of these photographs. Nevertheless, our photographs allow us to experience the world in a different way and allow us to create maps and metaphors of our journey in life. They provide us with a belief that we have control over our lives and as such give us a feeling of hope (Webster, 2000).

Our hope is that the photographs not only contextualize our told stories, but also serve as tools to make invisible lives increasingly visible. We are confident that our images not only reveal broader cultural, social and political stories, but also disrupt the official story. In order to see and understand the stories and photos one must be willing to accept the tragic dimension of aboriginal life. This dimension has greatly shaped the women's stories and most of all has robbed them of opportunities, dreams and possibilities. Yet, we also hope the reader can look beyond the surface of visibility and see that the stories tell of the moments where the women fought, survived, loved and lived.

The photographs and stories are subjective experience, as much as they are part of a cultural memory. "Photography has been, and is, central to that aspect of decolonization that calls us back to the past and offers a way to reclaim and renew life-affirming bonds. Using images, we connect ourselves to a recuperative, redemptive memory that enables us to construct racial identities, images of ourselves that transcend the limits of the colonizing eye" (hooks, 1995, p. 64).

The stories are told and the photographs are shown in order to trouble the readers' and viewers' images and memories. We want others to look outside themselves and begin listening to personal experiences, to enlarge and deepen their understanding of experiences, to recognize that policy decisions affect peoples lives, that policies are always lived out on the personal landscape. We trust that some of the stories and photographs elicit visceral, emotional, and spiritual reactions, to remind peoples of their relational responsibilities and to withstand the othering.

We hope that these shared images are able to resist and contest common ideologies (Hirsch, 1999) and raise questions. "Resistance becomes a question of the very line between visibility and invisibility. Only the most subtle, complex, and multi-layered reading practice that consistently confronts the personal with cultural, political, and economic meanings, will locate the resistant elements of a photographic image and will itself be able to produce resistance to the ideologies supported by the medium" (Hirsch, 1999, p. xv).

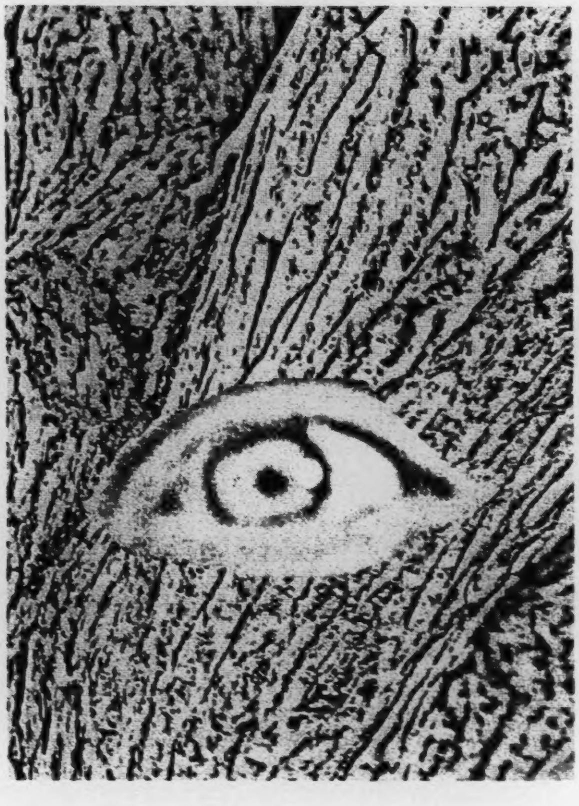
At the outset our stories were not intentionally shared to resist common images and ideologies. However, moments of resistance can inevitably be found in our stories and photographs. In retrospect, it was as if these moments simply found their way into the camera. In essence it was as if the photograph took us (Weiser, 1975). We worked hard at times to gain control, to camouflage the truth, and to exercise control, but nevertheless the moments continued to make it into the camera. It is in these pictures that our personal experience blends with our theoretical, political and intellectual beliefs.

Our photographs are also important ways to remind us of our visibility in our personal lives. "Photographs provide a way of keeping visual recollections of the past safe from the dulling grasp of time; so we store them with care, cherishing them" (Berman, 1993, p. 13). Photographs reaffirm our connections with others and they help us to break out of self-imposed silences; they become life affirming, and remind us of shared life experiences, our accomplishments, and good times. "Family albums are usually made for record-keeping, as talismans against the vagaries of time's passage, and a proof that people's existence and relationship with others have mattered and made some difference in the world" (Weiser, 1993, p. 25).

In as much as photographs provide insights, document our multiple perceptions and life experiences I urge you to think about the places, spaces, moments, and emotions that don't make it into the picture. The times where we refuse to have photographs taken of ourselves, or the times we do not take photographs. Sometimes these are times when we are deeply troubled, or our physical or emotional, psychological or spiritual well-being is at risk.

Tôhkâpi

have one's eyes open



the inner eye/I

At times I find it difficult to sustain my own subjectivity and identity against the encroaching academic world in my life. After spending hours worrying over typed words I catch a glimpse of my yellow rain coat hanging in the corner at the front door. The rain outside seems like an invitation to put on the yellow rain coat and my old rubber boots, which still carry the mud from the last few summers in between the tread of their soles. Walking along the river valley trails, feeling the rain run down my neck and listening to my own breath I realize how much I have neglected my own physical body. Amidst the rain I sit down underneath a tree at the edge of the riverbank looking across the river, wondering about my own life, about my identity and who I am in relationship to these aboriginal women. What truly is my role in documenting the lives of aboriginal woman? Why was I drawn to this continuous dialogue amongst ourselves? My thoughts wander, thinking about my own past, my actions and inactions in life and most of all about my childhood home. As I slowly begin to make my way back I can hear my voice talking to me. It was in this dialogue that I was awakened to my deep longing of returning to my childhood home.

Over the last few days my thoughts and glances return to my yellow rain jacket often and I wonder how will I write about my own life. Perhaps part of writing about my life is writing about the relationships the aboriginal women and I have formed over the past months. I place myself amongst them, refusing to write or talk from a podium of knowledge. I know I do not have the ability to represent their lives adequately; it is only through our conversations that I can see the multiple identities and stories they live in their daily lives. This does not mean that either one of us tells all there is to tell; we never do this. There are secret spaces in our lives and histories that we do not share with others and at times are unaware of ourselves. Some of the women are particularly silent about their childhoods, traumatic events, and lost or shattered relationships. I begin to wonder if the silence is an indication of how disruptive these events have been in their lives and their ability to form an identity.

Perhaps the most difficult times throughout my relationship with the aboriginal women was seeing them captured by substance use and having to witness the severe impact their substance use had on their lives, their lover's, children's and family's lives. It was during these times that I became attentive to the continuous reinvention of ourselves, of who we are and how we make sense of our life experiences. The women always reminded me that there was more than one way to live our lives and more than one way to live by our stories. "People organize their personal biographies and understand them through the stories they create to explain and justify their life experiences … it is the way they understand their own lives and best understand the lives of others" (Richardson, 1995, p 209-210).

I began to see how we continuously (re)construct and (de)construct ourselves in multiple ways and how we create new stories and reinterpret them as we come to know ourselves in a different way (Hindman, 1993). As women, we always attend to multiple conversations and happenings at the same time, being continually pulled in different directions. The women and our conversations were often difficult to follow in the transcripts, interrupted by the calls of children, steaming pots, or telephone conversations, while washing dishes, sweeping kitchen floors or sorting through clothes. However, we still always remained attentive to the story at hand in our conversations. At times I saw these multiple patterns of attention becoming synonymous with the carnival of identities present in our everyday lives.

Amidst the carnival of identities I was struck by how many of the aboriginal women's stories carried the theme of survival. Perhaps it is that "the theme of survival, of continuation, is a foundation for the act of storytelling in oral cultures" (Leen, 1995, p. 3). It is also a theme that shaped the women's identities.

The (dis)rupture and cultural discontinuity in their personal lives was and is critical in their identity formation. The influence of historical and social trauma, in particular discriminatory and exclusive happenings, shaped their identity strongly. All the women told and (re)told their wish to establish stronger cultural bonds. The woman's histories, both social and personal, differed greatly from my own. It took patience and persistence on their part to make me understand the multiple interpretations and cultural complexities they had experienced. Some of the women had been able to reconnect with their culture and most often this was after their HIV positive diagnosis. Two of the women described their (re)connecting as a new sense of identity; one in which they reconnected with a larger community, and one in which they were less isolated.

The women drew spiritual, emotional, cognitive and physical strength from their values, beliefs, and traditions (van Uechelen et al, 1997). The women survived difficult times, prejudices and paternalism and formed their identities by telling stories and by receiving stories from others and passing stories on to their children, "by literally and figuratively generating cultures" (Mullen Sand, 1992, p. 289). For some these stories were strongly linked to the physical landscape, to the places they had been, and to mother earth (Marmon Silko, 1996). Thus, places and spaces become a large part of our dialogue, one which requires attention to detail.

Stories are often being told amongst family members and relatives; many of the women said *after all, family is all I have*. The pull of family ties was strong for all of the women and often connected to their spiritual well-being. Mothers played perhaps the most central part in the women's family stories. The loss or inaccessibility of their mother was not only equated with the loss of love, home, and shelter, but also family connectedness. The loss of their mothers also meant a loss of their own histories and identities, since women often think back and are connected with family stories through their mothers (Behar, 1996). At times too the loss of their mothers meant a loss of someone to provide physical care when they were ill.

As women, and mothers themselves, they rejoiced and at the same time struggled with their roles as primary caregivers and nurturers of their families. The struggle was particularly difficult when other family members were also diagnosed as HIV positive.

Sometimes the women had a difficult time disclosing their HIV positive diagnosis to family members out of fear of being abandoned or rejected. Many of the women worried that their children had been exposed to the virus, as many were unsure of when they had became infected. Fear, panic, isolation and depression were common for all of the women at the beginning of their diagnosis and the acceptance of their diagnosis came much later for some of the women. Others still have difficulty accepting their diagnosis, continue to feel isolated and alone in their struggle to cope.

Being diagnosed with HIV also affected the women's ability to maintain their identities. All of them experienced stigmatization and discrimination. Many had been told in various ways that they were bad women, undeserving of appropriate care, attention and respect. Health and social service providers often told them to stop having sexual relationships, yet "the ultimate message behind the demand not to be sexual, is not to be human" (Maeve, 1999, p. 62). In the face of this adversity, to resist dehumanization, it initially became difficult for the women to find hope, meaning and direction. In addition a positive diagnosis of HIV brought with it shattered dreams and future possibilities (Nicholas & Schilder, 1997). Recounting the time of their initial diagnosis some of the women remembered, like others, reactions of "shock, fear, anguish, and suicidality. The impact of learning that they were HIV-infected often took its toll in unrelenting misery, escalating drug use, transmission risks, and destabilization of relationships, income, and shelter" (Stevens & Doerr, 1997, p. 523). Health care providers struggled with the women's behaviour and often attempted to reprimand them. However, as one of the women stated *I don't care what anybody says, and I don't think anybody would do anything different from what I'm doing.*

For some women however, once they came to terms with their HIV positive diagnosis, it became a catalyst for growth and incentive to change their lifestyle, personal relationships and to develop life and career goals (Siegel & Schrimshaw, 2000). They wanted to live every moment of their lives, particularly helping others make sense of their lives either as children or adults.

The women's HIV positive diagnosis marked a turning point in their lives (Mill, 1997). Their HIV diagnosis often came as a shock to these women, many did not know or had believed they were not at risk. However, through retrospection they can clearly identify the behaviours that placed them at risk. Their diagnosis forced them to look at their past, present and future and slowly construct a story of possibilities in the face of their many obstacles. In spite of everything they had to make sense of their lives. Several of the women continued to emphasize that there is a reason for all things; as one said *there is a reason the creator did this*, acknowledging the spiritual aspect of making sense of our identities.

Telling our own stories and writing about our lives meant having to think and ponder about our past, present and future and to look at our stories with an enlightened eye/I, to be gentle to ourselves as we map the landscape of our stories. Throughout our conversations and writings the women and I thought about how vulnerable we would become if we told our stories, how others might read and interpret our stories. Yet writing from our own perspective was also a form of resistance (Gates, Church, & Crowe, 2001). It was not only to resist the stereotypical stories of HIV positive women, it was also to extend the women's lives in face of "mourning and remembering their parents, grandparents, and great-grandparents, and of escaping and laughing at death" (Behar, 1996, p. 79).

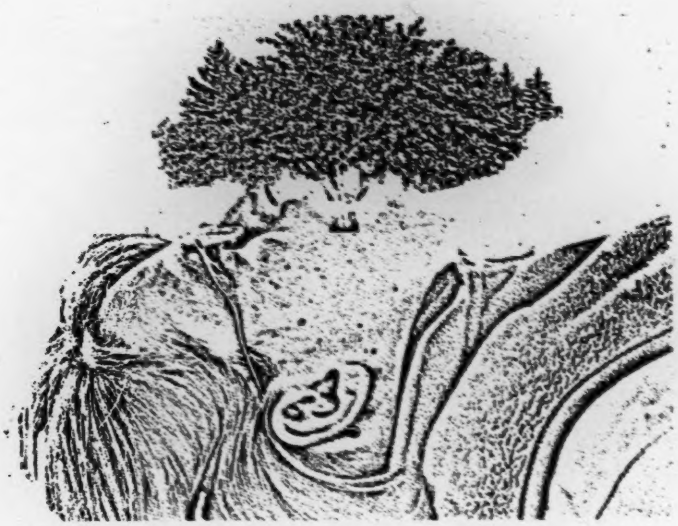
The women were passionate about talking and writing about their lives and invested endless energy into our conversations. Moreover, they were precise in their tellings and often asked if the tape recorder was working and when the next transcript was ready. It was as if in talking and writing about their lives the women became more intimately connected or reacquainted with their lives (Kuhn, 1995) and at times they were surprised later as they read the transcripts or the books about their lives. At other times there was disappointment, particularly if the told or written story was not like they remembered or there were missing pieces they thought they had included. I also sensed disappointment when the photographs they had taken did not show what they intended to, if they had forgotten to turn the flash on, or showed things, places or people inadvertently.

Writing about our own lives was difficult as there were "so many stories; so many voices telling one huge, complex, multitudinous story, a story so long no single novel can encompass it, a story so vast only the concept of cycle begins to hint at its dimension, a story so complex that only the greatest variety of devices, techniques, point of view, styles, and stances can justly reflect its infinite glittering facets, plumb its mysterious multitude of tunnels and hidden corridors" (Gunn Allen, 1998, pp. 145-146).

As the women and I read one last time through the printed words on paper we wondered if perhaps we need to start again, make one more attempt to get it right. Would we tell a different story? After all the stories were fragmented, nonlinear, and possibly being told for the first time. Yet the energy expended to document the details and complexities over the past years has been great already, and so maybe tomorrow we will start again, but not today. And as much as our stories have brought us together and let us use our imagination, they also pulled us apart (Kuhn, 1995), and at times forced us to revisit our worst nightmares.

As I trouble over the final words I can see that at times I am hard pressed to sustain my own subjectivity and identity against the encroaching academic world in my life, where there are few spaces for reflexivity. And I turn to my yellow rain coat and rubber boots, head out the door …

augenblicke



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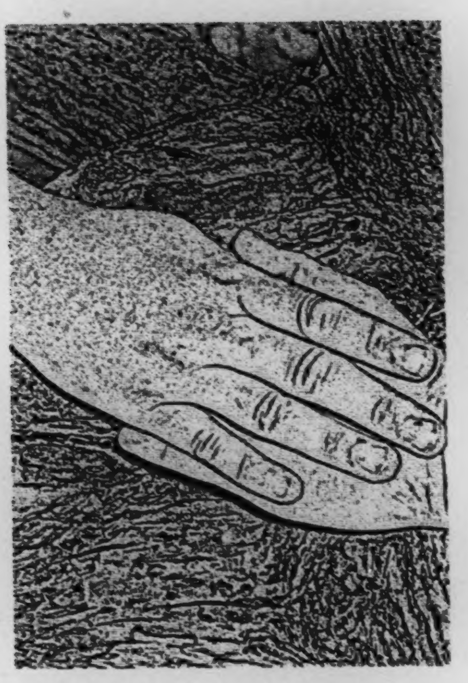
ceremony



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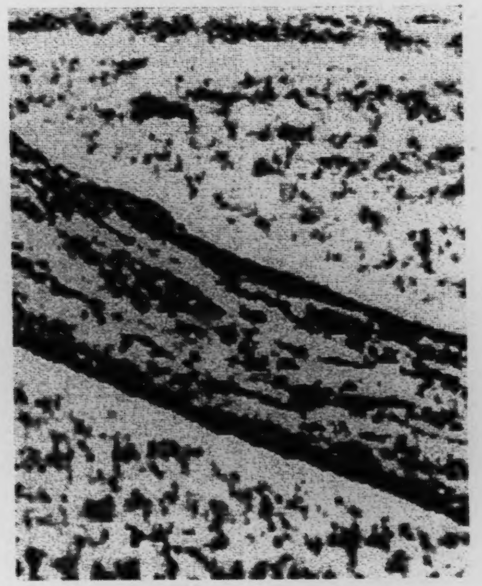

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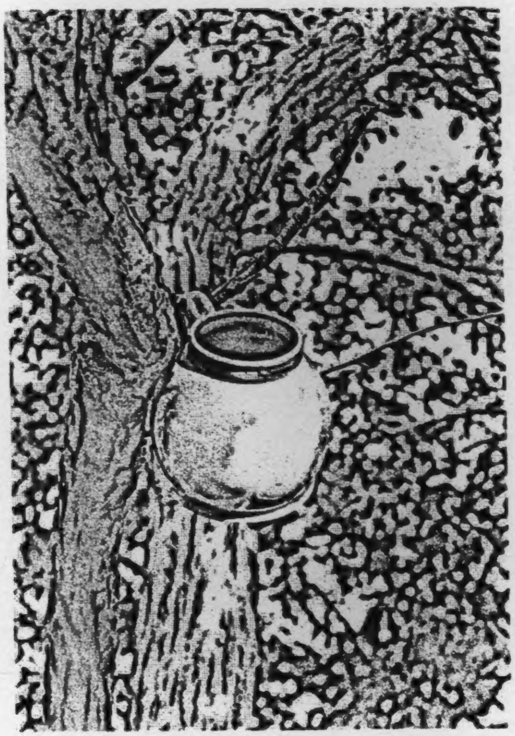

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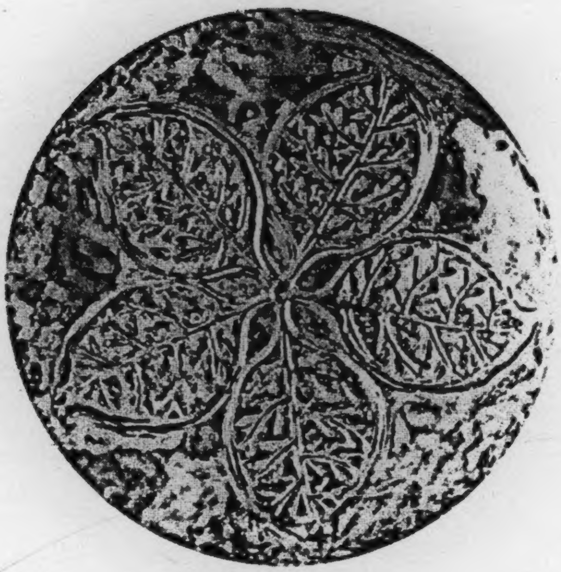

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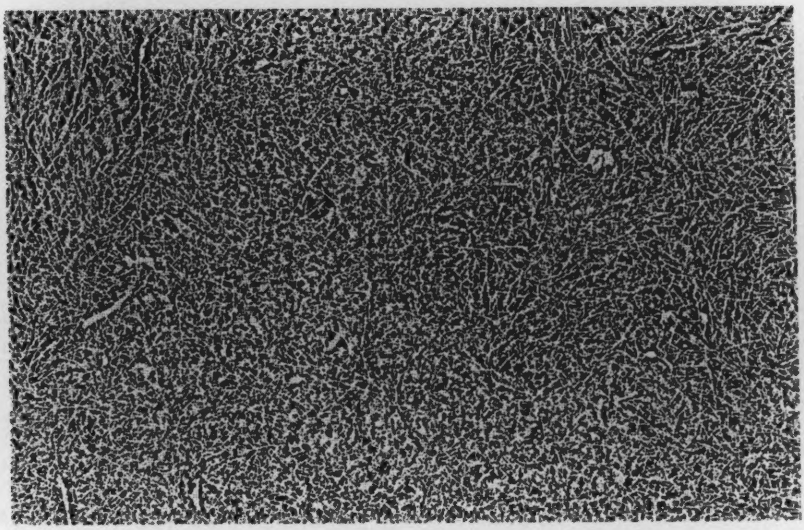

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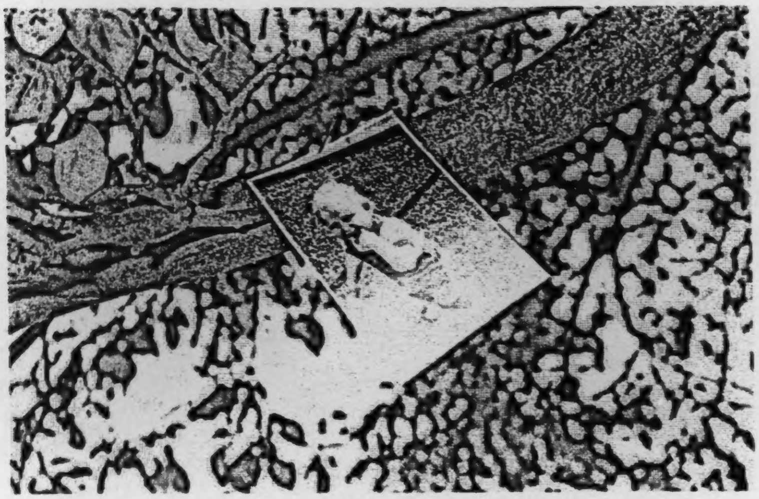

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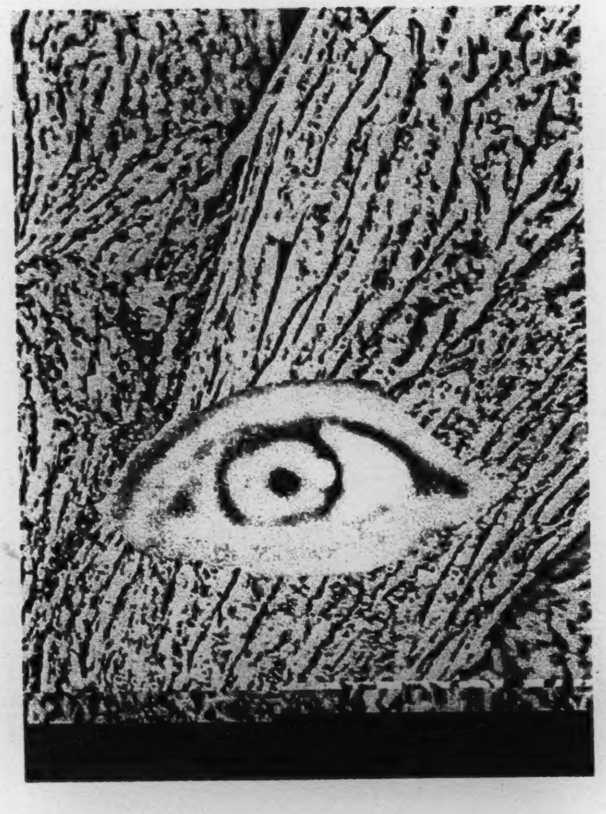

juxtapose

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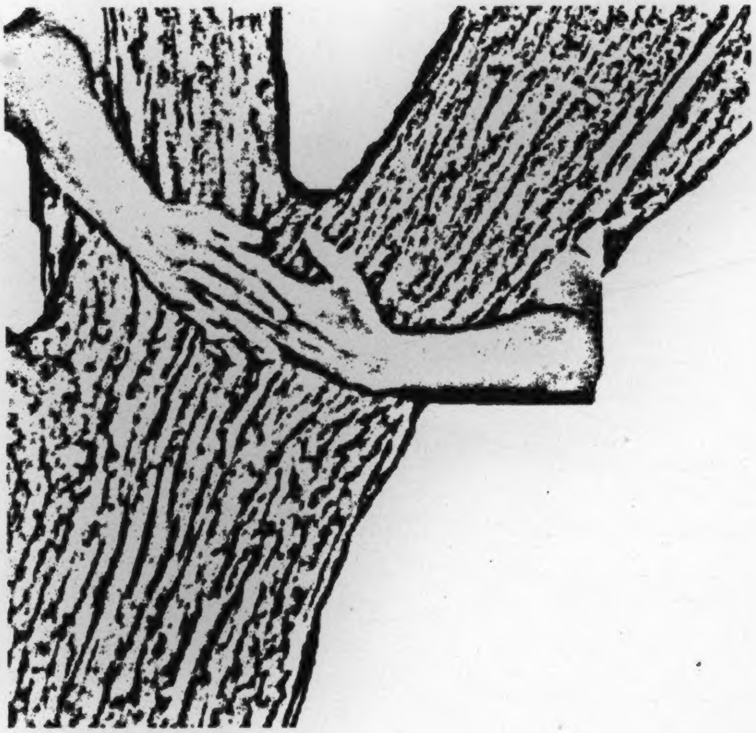

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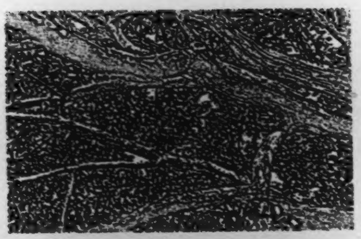

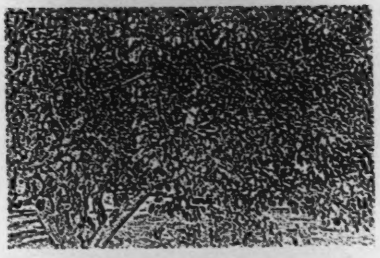

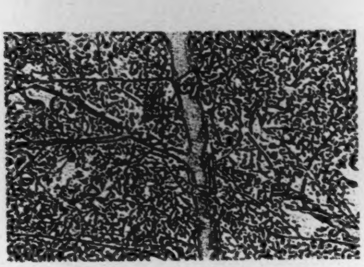

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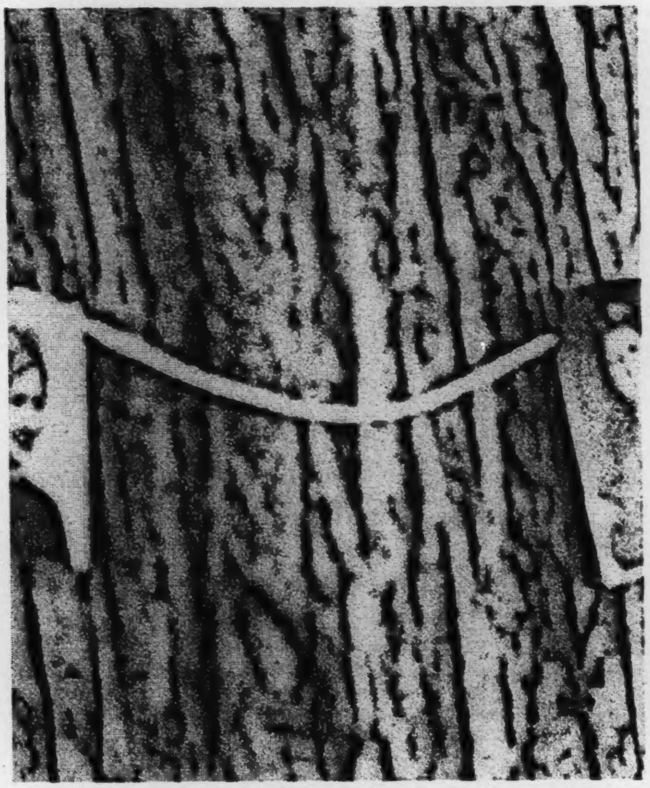
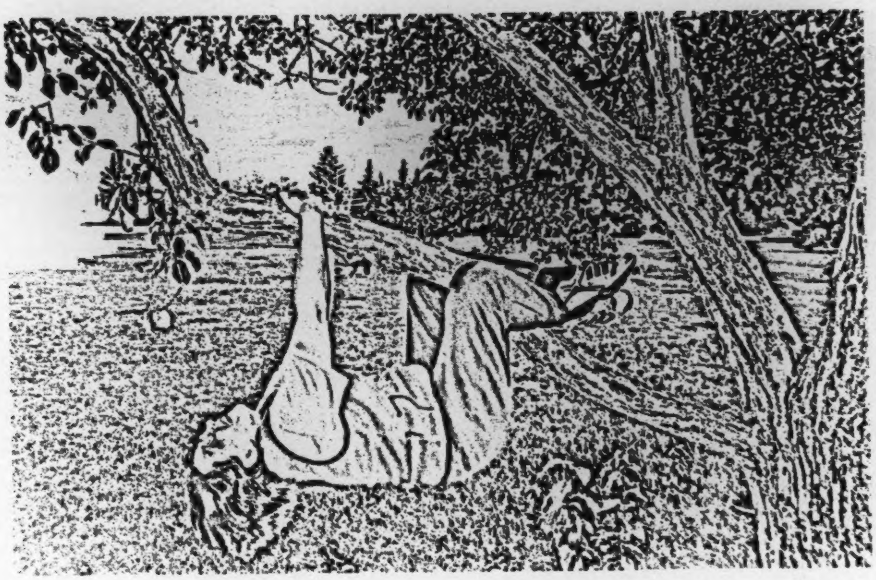


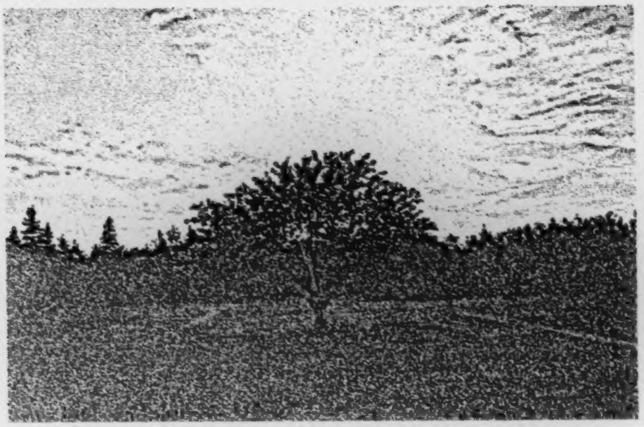
nightmare



ocean of tears

passion

quiet

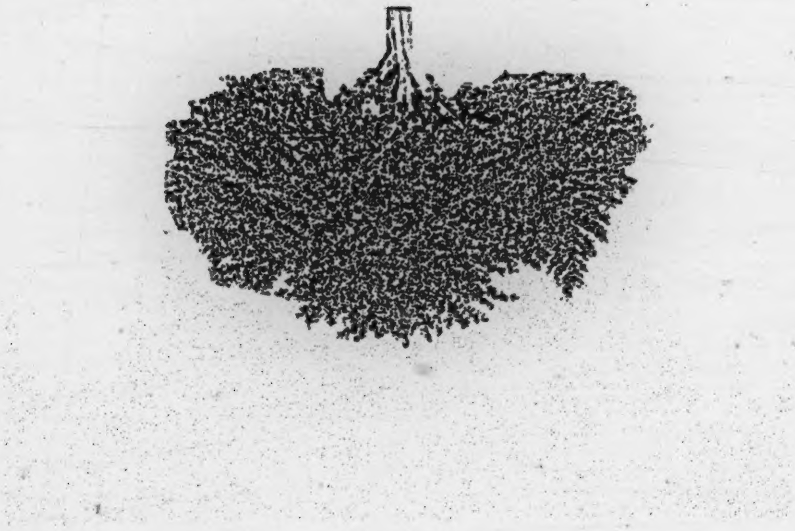


reflections

self portrait

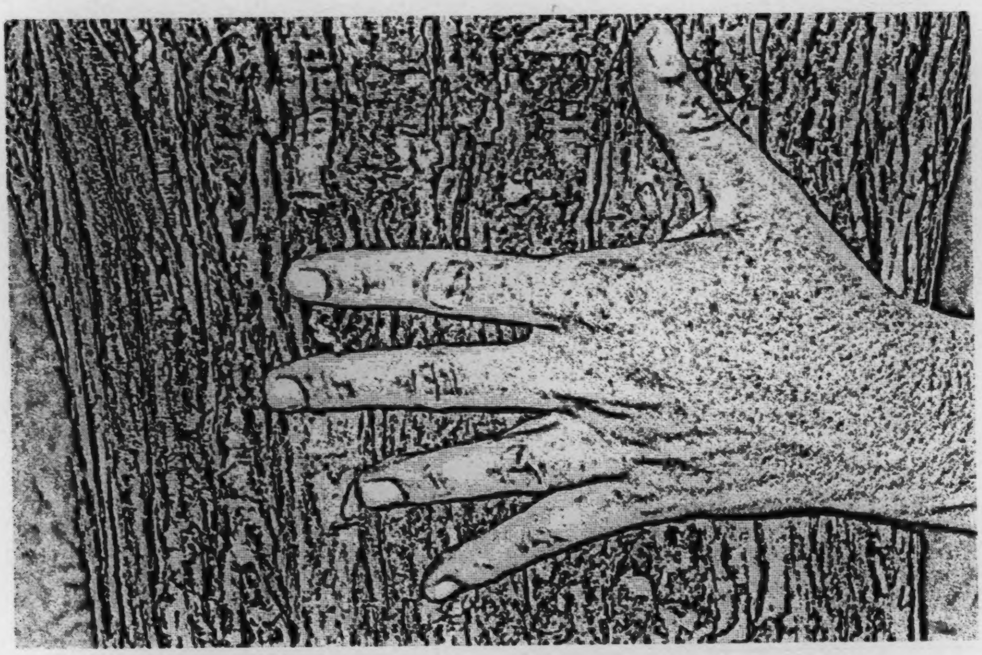
truth

unnamable



voices

writing



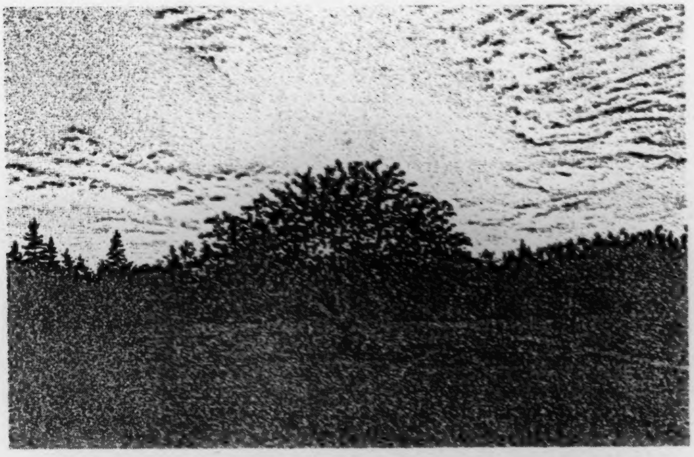
xenophobia

yearn

zeal

silence

It took time for me to be comfortable with silences and long pauses in our conversations and encounters. I had to learn to pace my wonders and puzzlement. Sometimes the silences become prolonged and the women reminded me: *I am not sleeping. I have a lot on my mind.*



Being attentive to our lives as narrative inquirers means to listen carefully to the stories of our own and other's lives, and it means to be attentive to what is not talked about, to the pauses and silences (Clandinin & Connelly, 2000), because stories both told and silent are always present and can be very powerful.

When we hear about aboriginal women living with HIV, we hear narratives of a marginalized population not stories of individuals. Hiding behind this larger narrative enables us, as a society and as individuals, to avoid looking at who we are, that we too are part of the current social injustices. More so, it continues to deny aboriginal women living with HIV a face and an identity. Presenting problem focused statistics and models on risk behaviours continuously reminds us that our individual strengths, abilities and potentials do not matter and they pathologize the stories of our lives; racism inherent in these images renders our stories invisible (Lorde, 1984). The data commonly presented about aboriginal communities and peoples portrays them as diseased and chaotic. It is these same images that are used to justify continued paternalism and dependency on non-aboriginal peoples (O'Neil, Reading, & Leader, 1998). Moreover, inherent in the abstract re-presentation of lives, is the reminder that our stories, explanations and making sense of our lives do not matter.

In our conversations the women sometimes talked about how they were defined and criticized by many, and how much of the criticism by others was based on assumptions and reflected class-based beliefs and values. The women's actual life experiences were ignored and were often not seen by the wider community in which they lived, the institutions that provide services to them. It appears that as a society we suffer from collective amnesia, one which continues the perpetual silencing of the lives of aboriginal women.

Research too is silent on how aboriginal women with HIV frame their lives and the complexity of their everyday moments. Not knowing, not seeing the lives and the complexities of these women actually provides us as individuals with a means of unlinking their life experiences from communal responsibilities. The lack of communal responsibilities in return, enables us as a society to avoid any serious long lasting attempts to ensure the health and future of aboriginal women's lives.

As a society we have powerful institutions that do not hesitate to perpetuate the hardships and difficulties aboriginal women experience. Indeed these institutions, such as social services, health care, police and justice systems often set people up to fail, rather than assisting them to succeed. Throughout all the meetings with social workers, lawyers, police officers and health care providers I attended, all cited larger institutional policies from preventing them from offering assistance that would make a positive difference. Interestingly however, throughout all of these meetings, I did not see any evidence of personal lobbying or opposition to existing policies by service providers. In fact, I was responded to with the shrugging of shoulders when asked why assistance was not offered which was interpreted by the women and myself as carelessness, resignation and complaisance. Many of the women were extremely fearful of any contact with service providers. *It's scary for me, because if something else goes wrong and they have to keep my children, and now they know I'm pregnant, I'm scared they're going to take the baby.*

Some of the women attributed the silencing behaviours of care providers directly to their HIV positive diagnosis, their risk behaviors, or to their aboriginal heritage. Dion Stout, Kipling, and Stout (2001) state "[a]boriginal women also emphasized the toxic role played by racism and sexism in undermining their health and well-being, together with the detrimental effects of poverty, unemployment and culturally inappropriate or inaccessible health services" (p. 22). For some women the encounter with discrimination become a daily fight, one in which the outcome seem almost pre-determined.

Returning to the transcripts I can see how our initial conversations were frequently filled with hesitation, uncertainty, vagueness, and brevity. It took time for the women and I to establish trust. Over time I began to see that instead of being silent by choice, it was fear and trepidation that made them hesitant to tell their stories to me. Like other women they were isolated, secretive and preferred to be invisible (Nicholas & Schilder, 1997).

At other times it was the circumstances in which the aboriginal women were born that determined their life stories and their stories to live by. *Well, I raised her. My parents were party-goers. My sister was also — she had a very bad drug habit, so she wasn't capable of taking care of any baby at all. I was the only one that was taking care of my two younger sisters. My younger brother was already potty-trained, so I didn't really worry about him. I fed him and did the necessary things, but with my two younger sisters,* *I was always there for them. Plus I was going to school. I couldn't stay up very late. Even when they got sick, I had to sacrifice my sleep to take care of my younger sister. My parents didn't come home.*

The women too realized that they were silenced by their own histories and behaviours. The women, who had experienced substance use realized that their addictions were robbing them of their ability to make sense of their lives, or to be parents to their children. The silence within their own history and the silencing behaviours of others placed the women in spaces of social isolation, which in turn created a tremendous amount of dependency. A dependency that includes not only substance use, but also forced some women to continue working in the sex trade and/or to become dependent on lovers and spouses.

Living life dictated by silence was difficult in that the "telling of a story, however it occurs, is part of the living of a life and that to shut a story down is to shut down, as well, the life of which it tells and from which it flows" (Neumann, 1997, p. 108). Therefore, I continued to encourage the women to tell their life histories, to nourish and sustain themselves in whichever way possible.

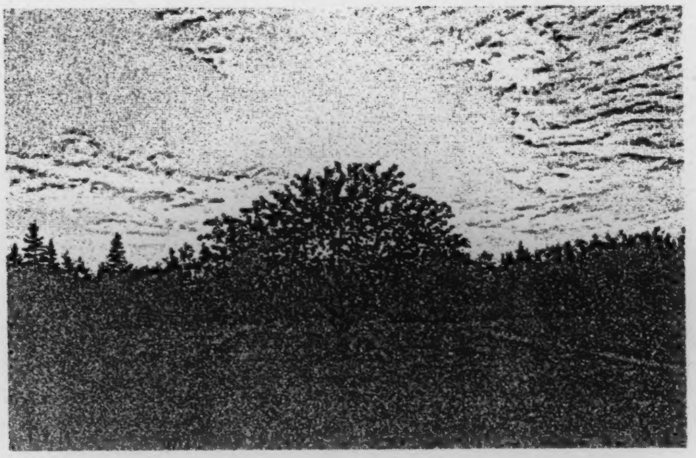
Gaining voice and experiencing a shift from silent to told stories was difficult work. It was not easy to build the trust, to create a safe space in which to tell stories and I remember my continuous search for appropriate responses. How do I respond to stories? Encouraging voice creates vulnerability, despair amongst closeness, pleasure and growth. What do I leave behind? The recognition of shattered dreams or lives or the realization of potential and possibility? The continuous search for appropriate responses left in me a trail of worries and anxieties, and a mistrust in my spontaneous abilities.

Like the women I had to trust my voice and "[a]s in many American Indian stories, there is a theme of transformation and restoration to harmony" (Tafoya, 2000, p. 58), which also was present in our stories and conversation. "Though perhaps for those of us who have learned silence through shame, the hardest thing of all is to find a voice; not the voice of the monstrous singular ego, but one that, summoning the resources of the place we come from, can speak with eloquence of, and for, that place" (Kuhn, 1995, p. 103).

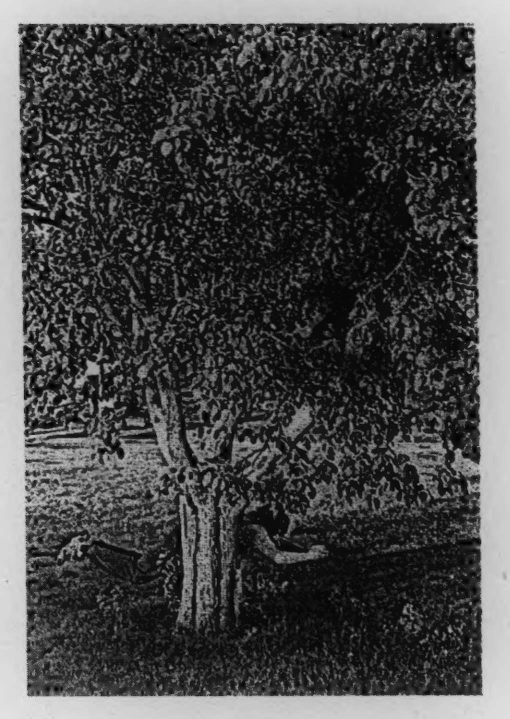
Voice was an important element throughout our journey together and in particular used to break the silence that surrounded so many of the aboriginal women's stories. We were aware that finding voice and unearthing silent stories was not inconsequential and that we had to remain careful (Devault, 1990) and attentive not to cause spiritual, psychological, emotional or physical harm.

Finding voice has not been an easy process and I am reminded of how privileged I am to have found a space in which I can write, read, explore and imagine (Minh-ha, 1989). Throughout this study I not only had personal spaces in which to engage, but also a larger supportive community that continuously reminded me that "the remembering and the retelling [are] communal processes" (Marmon Silko, 1996, p. 31). The remembering and (re)telling in a larger community made me aware to the fact that many of our stories are interconnected, intertwined with countless other stories, ancient stories and stories not yet told (Marmon Silko, 1996). And it was that "classrooms, halls, grounds, and community – become memory boxes [for me] in which people and events of today are re-told and written into the research texts of tomorrow" (Clandinin & Connelly, 2000, p. 66).

Although the women and I were troubled by many silent stories, there was also a recognition and appreciation that silence was rich, complex, multilayered and embodied mystery. I began to see with time that much of our therapeutic work was happening in silence and that silence provides a space in which we make sense of our lives. “So we sometimes say the moment is alive again within us, within our imaginations and our memory, as we listen” (Marmon Silko, 1996, p. 43), listen to the voices and silences present in all of our lives. In our encounters and conversations silences, pauses, hesitations and brevities were a language of their own. “I have become accustomed to the silences, blanks and lapses that set in when the work becomes to dense, to clustered and tangled … they provide room to breath” (Trinh, 1989b, p.373). Perhaps the biggest challenge for me in understanding the language of the aboriginal women was to understand the language of the unsayable, the language of silence.



difference



Not only were the women and I different, the differences amongst the women varied greatly as well. We were all positioned in multiple ways, depending on our life experiences, and in particular our political, economic, historical, genealogical and cultural experience (Smith, 1999). Our positions shaped our conversations and the words with which we had to express our experiences. The inability to verbally express their experiences became challenging and frustrating for the women at times, the continuous searching for words, in particular when trying to express their emotions, inner thoughts and feelings. Sometimes it was about finding the right words and at other times it was about being given the opportunity to express their feelings and emotions for the first time, without feeling judged or censored.

At times the women spoke a language that was unfamiliar to me, a language filled with cultural symbols and images. (Re)thinking our conversations and (re)reading the transcripts carefully I can see how many of the women talked about their cultural experiences and were markedly different in the expression of our dreams. The women were much more conscious of their dreams, they were able to recount them and often contemplated them. Multiple conversations with some of the women focused on their dreams, that were described as powerful, compelling; awakening them to long lost people, places and spaces, even at times dreams pointing to future events. The dreams were always significant for the women in making sense of their lives.

The women and I were also from different cultural backgrounds and this too shaped our conversations. Although I had worked with aboriginal communities in northern Canada, as well as alongside aboriginal peoples living in the city, I knew that there was much to learn and be attentive to. The women remained patient with me throughout our conversation, sharing their cultural knowledge at times, aware of what was not appropriate to share at other times. Throughout writing about our conversations we were careful not to write about ceremonies in detail, to not disturb ancestors and spirits. These parts of our conversations were also never audio taped, or erased immediately when we had been unaware of the inadvertent audio taping throughout our conversations.

Although the appreciation of difference enriched and deepened our relationships we were aware that the construction of difference is often part of oppressive practices, racism and sexism. The women were aware that their HIV positive status placed them amongst a very stigmatized group of people, that many defined as being different and most of all, irresponsible. As women they were frequently blamed for their HIV positive status. And so the women were not only held responsible for their HIV positive status, but also for being different (Abrums, 2000).

The concept of difference also includes the idea of otherness and rigidity (Bhabha, 1994). The categories and labels applied to peoples or groups of people tend to be fixed and seen as unchanging, placing peoples in inevitable positions. "In other words, [categories and labels] are not the difficulty; it is the inflexibility and tenacity with which they are created and asserted that creates the problems" (Pillsbury & Shields, 1999, p. 413). This was particularly troublesome to the women. Since they were aboriginal women many service providers and non-aboriginal people presumed they lived a dysfunctional lifestyle amongst chaotic life circumstances. As well, whenever the women disclosed their HIV positive status it was assumed that they were using illegal substances and engaging in high risk sexual activities. There was a strong belief by many service providers that the women were unable to stay away from substance use for any length of time. Many of the women recalled continuous pressure from service providers to admit to the alleged substance use and participation in high risk sexual activities, something other women and men have experienced as well (Lawless, Kippax, & Crawford, 1996). At other times service providers believed that the women's HIV positive status rendered them unable to provide childcare. One of the women has a strong supposition that her children remain apprehended from her because her HIV positive status is known to the child welfare worker. The responses, reactions and subsequent actions of others has strongly shaped the women's illness experiences.

Although attempts have been made to disassociate "HIV from high-risk groups – black, aboriginals, gay men and prostitutes – [this disassociation] might serve to dilute the social justice issues previously attached to HIV. No longer will the undemocratic character of HIV be evident, because HIV will now be presented as touching everyone" (Jackson, 1997, p. 33-34). Hence access to resources for members of high risk groups becomes increasingly difficult.

Although the differences amongst the women and between the women and myself pressed us to be patient, and at times provide lengthy explanations to help each other understand how our position in life had been shaped, the differences were also invigorating and sparked new insights and ideas. "It is learning how to take our differences and make them strengths. For the master's tools will never dismantle the master's house. They may allow us temporarily to beat him at his own game, but they never enable us to bring about genuine change. And this is only threatening to those women who still define the master's house as their only source of support" (Lorde, 1981, p. 99). It did not take long for the women and me to overcome the threat of our difference and begin to see where our lives intertwined as women.

Differences too can be seen in our photographs. My own photographs represented abstract ideas and concepts, while the majority of photographs taken by the aboriginal women were of family members, lovers and friends and primarily reflected their intimate personal relationships. Their photographs also were stereotypical at times, depicting what a family was to look like, of happy and joyful moments and keeping moments of sadness, disappointments and tensions at a distance. Only looking at the photographs one has to look closely and ask questions to reach the deeper meaning and to hear the silent stories.

The women's photographs forced me to look at my own family albums and to see patterns of representations. To identify the ways people photographing my family saw us, or members within my family wanted me to remember my childhood. My photo album also entailed silences. From my experience of the first few years after I immigrated to Canada I have very few photographs and I know it was a difficult time for me. As an immigrant woman I know what it means to live in two countries, or across borders. I long for my home country all too often, yet when I am there, I long for my new home in this country. Do I belong anywhere? In retrospect, questions of belonging were predominant. While looking at family albums with some of the women, I made similar observations that when our sense of self, belonging, and identity is deeply threatened we rarely ever take photographs, write stories or even remember. Perhaps this absence represents a feeling of difference, isolation and loneliness that emerges and one which leaves deep psychological, emotional, spiritual and physical scars.

Others have wondered about the mechanisms that erect and maintain differences (Pillsbury & Shields, 1999). Perhaps the absence of stories, photographs, images and dreams of times in our lives where we needed to challenge difference, protect our identity, and/or make sense of our lives provide part of an explanation.

At the same time that our story is being shaped by who we are, our personal stories are also socially constructed; influenced by social expectations and larger historical event. For example, social expectations were evident when the women were seeking help from government agencies. Some of the aboriginal women received financial assistance through various government programs and many times they were reminded both while completing forms, and while engaging with agency representatives, that their reliance on government assistance speaks to their laziness, lack of education, and lack of determination. Yet, many of the women looked after children, cared for their homes, made crafts, played music, wrote poetry and helped others in need. Similarly, Wagner (1994) recognized "an implicit assumption underpinning the debate on work is that lack of work means laziness, criminality, dependency, or boredom."

It is not uncommon for marginalized populations to experience labeling and to have their lives defined by others (Weiser, 1993). Wherever she goes she is asked to show her identity card? Where does she belong? How does she identify herself? The attempts by people to define and label them was often very confusing to the women and they spoke of how hurtful and damaging these encounters were to their self-esteem and their identity. As Weiser (1983) has pointed out this can be particularly damaging to aboriginal peoples or immigrants, “as they lose their sense of continuity and respect for their own culture and its roots” (Weiser, 1983, p. 177).

Throughout this text I use the term aboriginal to denote status and non-status First Nations people, as well as Inuit and Metis people. I use the term aboriginal peoples as opposed to aboriginal people to reflect my appreciation for the diversity of cultures, traditions, living circumstances, and experiences among aboriginal peoples.

At the same time there are still many characteristics aboriginal peoples have in common. As Dion Stout and Kipling (1998) point out "[a]lthough their numbers are relatively small in an absolute sense, Aboriginal women constitute a vibrant and highly diverse segment of Canada's population, who share a common legacy of marginalization and oppression" (p. 3). All aboriginal peoples have been subjected to racism, both overtly, through such legislation as the Indian Act or more covertly in schools and many other public and private spaces. Many aboriginal peoples are survivors of residential schools, or are children or relatives of those who have been victimized in these government organized and church run educational institutions. These forces impacting aboriginal peoples' lives have often been violent and outside their control.

Despite the multiple forms of historical, systematic and individualized racism the women, their families and communities had experienced, the perseverance of cultural and spiritual roots was evident in our conversations and the lives of the aboriginal women. As one of the women pointed out: *It is out of respect for our culture and that is where we get our strength from.* The cultural value of family, connections and interdependence was vital and contributed not only to the women's ability to cope, but also helped them establish a sense of health. The women's histories have all been significantly shaped by their families and I learned that "a person without a history is like a tree without roots ...our culture is the extended family" (Gledna, as cited in Orr, 2001, p. 194). For some the loss of grandparents, mothers or other family members also meant the loss of traditions and the loss of cultural knowledge and guidance.

At times however, family members added personal hardship to the women's lives. *Like I said, my family lives down like close by, and they are alcohol abusers and stuff like that, so we just want to stay away from that. I care about my family and everything, but they don't realize right now what we're trying to do. We're trying to live. We can't live like that no more, you know. We had that already, we lived that kind of life before. We* *didn't really like it. It's over. We chose not to have substances in our house, just you know to benefit ourselves, our children — especially our children.* In order to protect their own children some women chose to stay in very distant contact with their parents or other family members and at times severing all ties for extended periods. This attempt however should not be seen as a break with their cultural roots, instead "in the smiles on the faces of our children, you see the reflection of peoples who have come through many trials and tribulations but who continue to exist today because we have not consented to allowing our traditions and our way of life to be negated" (Cajete, 2000, p. 186).

Almost all the women expressed a strong wish to learn more about their cultural heritage and to participate in ceremonies. Participation in ceremonies such as sharing circles, sweat lodges and smudges, as well as visits with elders and medicine men were seen by the women as most significant in maintaining and restoring their emotional, spiritual, mental, and physical well-being. Participation in these ceremonies was also seen as a way to maintain their linkages to their cultural roots and ease their wounds.

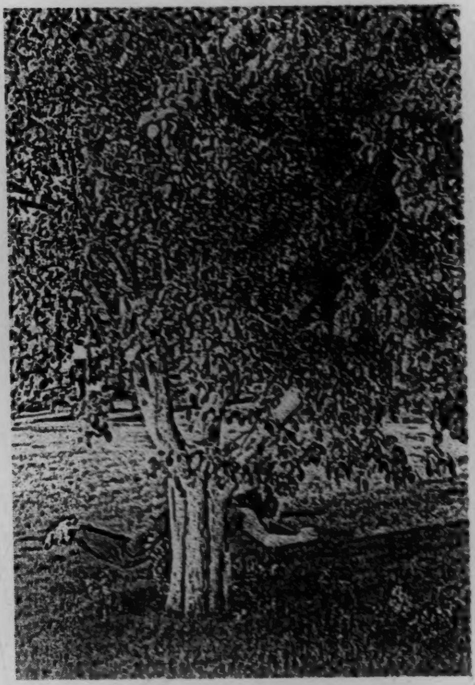
Yet ceremonies are not only restricted to special events or gatherings. "How you live your life is also ceremony. I have met many people who do not have the language, don't know any ceremonies, don't know anything about who they are as an Indian person, but they are the most traditional people I know. They are loyal, they are honest, they have integrity, they are caring, they know how to be respectful, they are all of those things that made our people who they are. All of those things that those ceremonies are meant to be" (Chaske, as cited in Anderson, 2000, p. 27).

being non-aboriginal

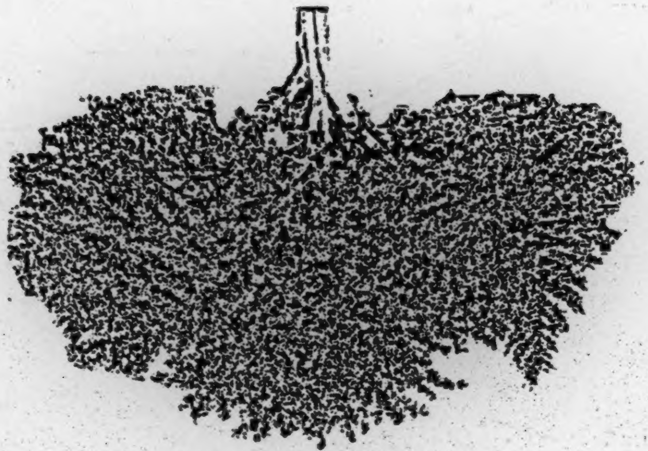
Thinking about being non-aboriginal and what it means to be aboriginal, in a personal way was hard for me. It meant thinking about how my own roots had impacted the lives of the aboriginal women, their families and communities, their roots. It was at these times that I wanted to evade the conversation, that my eyes glanced at my yellow rain coat and rubber boots for different reasons … to resist the tears and emotional impact of thinking about what it means to be white. Although a great temporal and spatial and cultural distance exists between the aboriginal women's lives and my own, my responsibility does not lessen. With time I learned that "nothing is that simple, […] you don't write off all the white people, just like you don't trust all the Indians… They want us to believe all evil resides with white people. Then we will look no further to see what is really happening. They want us to separate ourselves from white people, to be ignorant and helpless as we watch our own destruction …" (Marmon Silko, as cited in Minh-ha, 1991, p. 21). Therefore my search of what it means to be non-aboriginal and to be aboriginal continues with no clear answers emerging. Like the aboriginal women I too realize that "[m]y cultural identity is complex, but never confusing, except when I try to simplify it" (Solanke, 1991, p. 128).

I must however ask myself how much am I a part of the perpetuation of not listening and of keeping stories quiet, stories of my own and stories of others. Slowly, I begin to recognize how easy I have fallen prey to the belief of when and where it is acceptable to share my story, my identity, but not questioning why there is so much silence so often? Sometimes I am even surprised to find myself in my own stories – humming a song and telling a story, laughing and crying. I am present through what I have omitted to say, in stories I do not tell and where I have not placed myself. I can see how my story is at times left out in the conversations with the aboriginal women, reflective of my acceptance of made up academic rules of objectivity, rigor and value.

Creating places and spaces for the women and myself that acknowledged and respected our difference was important to us. Our respect for each other was mingled with affection, care and compassion and it was vital to hear all of our multiple voices in our conversations. Our conversations were marked by moments of closeness, but also moments of separation, where our difference stood in the way of understanding what we were saying to each other. Within the moments of closeness we recognized the resonance of our experiences, the overlapping of life experiences (Bateson, 2000). On the other hand, our moments of differences encouraged us to look again. "As we learn to know [each other], that mask of "otherness" splits open to reveal the inherent humanity that connects us all" (Tafoya, 2000, p. 59).



shifting patterns ~ talking back



complexity

The complexity of this narrative inquiry grew with time and increasing attentiveness to the multi-dimensional narrative inquiry space, with consideration of the four directions of inward, outward, backward, forward, and by locating the story within space (Clandinin & Connelly, 2000). At first this complexity was messy and confusing to me and it took time to realize that each layer of complexity helped me understand who each women was and what it meant to live with an HIV positive diagnosis. It took time to understand that stories of the women's lives were like gifts that grew out of multiplicity (Minh-ha, 1989). Each time I thought I understood parts of the women's lives, they pressed me to look again, to re-think and contemplate my previous understanding.

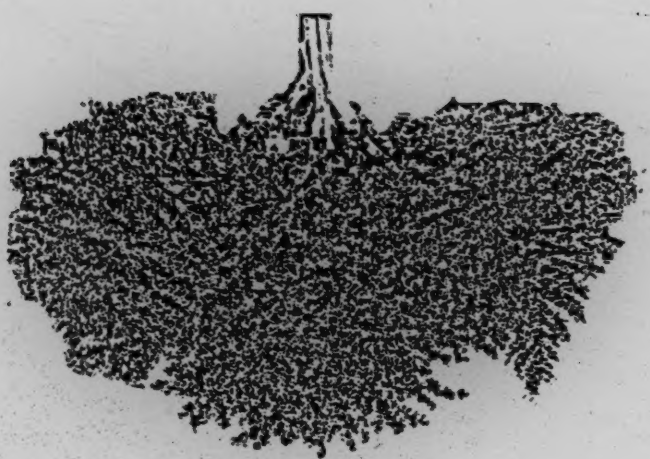
The women combined their old and new stories seamlessly and "eventually there [was] no division between the old and new stories. They become part of each other. They are dancing the same dance and sustaining active life in that dance" (Leen, 1995, p.4). Inherent in this dance was the energy and rejuvenation for future stories and possibilities to tell old and new stories, and every so often I saw a glimpse of a pattern, a moving of bodies in rhythms.

The women were not afraid to talk about their lives, they were not afraid to show photographs and stories of their dances. *You know what you can do? This one right here, you can put up, however, the whole thing, because [pause] I'm not [pause] like, if anybody wants to say something to me, bring it up. I ain't no weakling, and everybody knows already.* To make their private lives public was a way to talk back for the women, to gain voice amidst silence and as Minh-ha (1989) pointed out "let her who is sick with sickness pass on the story, a gift unasked for like a huge bag of moonlight. Now stars shine white on a black colored sky" (p. 2).

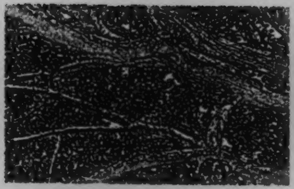
The flexibility and openness of our encounters and conversations enriched the stories, there were no scripts to follow, no limitations in the possible ways we could think and wonder about our lives. The women never stopped teaching me, urging me to re-think my position of knowledge, and question my position of privilege.

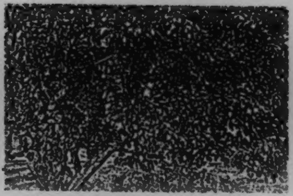
The most important part of our research for four out of the five women became the writing of their stories. The women wanted their own voices (re)presented, to read their words printed on paper to protect their lives from becoming meaningless, to sustain hope and to show that the human spirit is resilient. The women and I also thought about their books as a way to show the tremendous capacity, creativity and resourcefulness present in the lives of aboriginal women living with HIV. Most of all however the books are an attempt to work against existing racism and discrimination. Therefore, the books encompass stories of resistance to being boxed in, stories written with emotions, authenticity, stories that want the reader to respond.

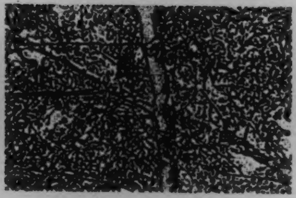
There were also much more personal reasons for the women to write their own stories. All of the books are dedicated to their children, lovers and family members. Some of the women thought of the books as leaving behind a legacy, a legacy that tells those intimately connected to their lives that they loved and cared, but also struggled.



beginnings







As the women and I worked diligently we recognized that perhaps the most powerful aspect of this kind of research is that it changes those involved in a very personal way. Because the work is personal and comes from the fullness, the depth of our experience, something new as well comes into view, something previously hidden under layers of life. Often after hours of work we sat at the kitchen table or drove in the car quietly, exhausted and in as much as our work has become a celebration of life and a renewal of hope we need to find rest and solitude. For all of us this work has confronted us with issues in our lives that were previously hidden or we did not know existed and we all have tried to address them in our own personal ways. I am slowly beginning to write again, carefully discovering what once was familiar. Writing long letters to myself, writing poetry interchanged with symbols and images, it is not as easy as it once was.

Throughout our writings the women and I have attempted to keep our writings simple, to avoid the heavy overlay of theories and abstract jargon, to ensure that almost anyone can read our writing and photographs. After all we did not want to fail people what they didn't already know, but to awaken the reader and viewer to their own critical and reflective abilities (Minh-ha, 1991).

The women did not want to write for an academic world alone, because then the stories might not be carried into schools to teach young women and girls. Neither did we want to write for those writing and analyzing policies alone, because then the complexity of our lives might not be heard and our stories would be dissected and fragmented. Finally, we did not want to intermingle our stories and tell brief excerpts alone, because then we seemed like one when there are differences amongst us.

As we meet to read our final printed words we begin to dance again, and contemplate patterns and pauses in the music. The stories and photographs we have shared with the reader are not the only evidence of our lives, they only provide a glimpse of how we have lived and how our lives have changed. The photographs and stories point to important and ordinary moments of our lives, they emphasize the importance of healing and the connection with family. As well, the stories have been a part of reclaiming pride and humility in aboriginal culture.

The women and my encounters and conversations have been moments in our journey, part of helping us make sense of our lives. It has made me realize how little I know and moreover wonder how much in our lives is forever untold, forgotten, and buried deeply. I am reminded that ambiguity, hesitancy and silence is part of our lives. That within the ambiguity lays room to recognize patterns, to shift patterns, to talk back, to find coherence and to share multiplicity (Bateson, 1994). That within ambiguity lays hope and a celebration of mystery and creativity (Ezzy, 2000).

The women's stories have touched my spirit, and made me aware that life itself is delicate, and that a community of caring can ease the fear of dying alone. Within the fieldwork and the writing of a research text we have formed friendships and bonds, marked by caring, trust and connectedness.

No reading or seeing or writing of a life story and lives is complete; there are always parts missing. Lives cannot be summarized neatly and entirely, and all we ever accomplish is to take notes, tentative explorations with a pencil and a camera to document stories without beginning or end, much like circles. Circles grow within circles and so maybe the next time we dance or "we sing that song, we will watch our circles grow" (Gunn Allen, 1998, p. 63). As we tell our stories, we hope others will join the circle and tell their stories, so we are not alone, to avoid being marginalized and dehumanized.

As we invite others into our circles, we ask for respect not only towards the stories we have shared but also towards their own storied moments, to find affirmation and encouragement in their own life histories and those around them, their family, friends, and communities … to listen carefully and to be attentive.

As we join the circle again we have a responsibility to keep the story alive, to acknowledge that peoples and places are always becoming (Clandinin & Connelly, 2000) and changing. In these final pages my thought returns often to the aboriginal women, to their storied moments and to our conversations; I continue to be puzzled by and wonder about the lives of aboriginal women living with HIV, my own and those moments we have shared over the past few months. In so many ways I am sitting here, waiting, waiting for someone to reassure me, and explain to me what happened over the past year.

As I look up I catch a glimpse of my yellow rain coat and my rubber boots standing at the door, waiting for me to get up, to walk the trails of the river valley and to begin to (re)visit and (re)think the storied moments in our lives journey. I am encouraged to look again

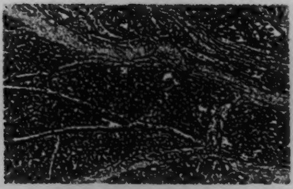
conversations with a tree

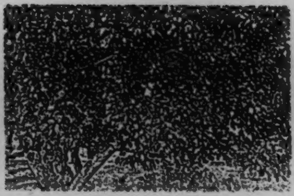
remembering long ago moments
across oceans ~ between mountains

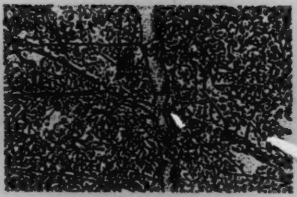
lifting my hands to cover my face
to smell the dirt and plants

recalling moments long ago
of conversations with a tree
older than I could ever imagine being
lived times I could never imagine seeing

yet through conversations
I became part of moments long ago and moments yet to be imagined







University of Albert

Storied moments:
A visual narrative inquiry of aboriginal women living with HIV.

by

©

Vera Franziska Julianne Caine

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Nursing.

Faculty of Nursing

Edmonton, Alberta

Fall 2002

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My journey written in song.

It's not all about HIV.

Debbie and Leonard in relation with Vera Caine

August 2002

When you live with HIV you don't take life for granted.

You look forward to each day.

You still got to move on, you still got to live.

You still got to embrace life even though it's not embracing you.

That's where the challenge lays;

knowing that you could easily fall by the wayside and die.

Leonard, November 2001

My journey written in song.

It's not all about HIV.

acknowledgements

honoring my grandmother

being Cree

the other side

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my boys

coming to terms with the virus

falling in love

a new life

dreams

acknowledgements

This book is dedicated to my little family.

To Leonard, my love,

to my boys and especially for my little angel.

Love, Debbie.

honoring my grandmother

Like Minh-ha (1989) Debbie too knows that her own life story is much older than her own physical body, or that of her mother's or grandmother's body. The story of her birth and death has been whispered in the wind, amongst the trees and open fields a long time ago ....

To honour our grandmothers means to honour life and to acknowledge what has become before us and what will continue to be. As Debbie remembers stories of her grandmother she recalls that *my grandmother has taught me a lot, and I will say my grandmother especially, because she — my grandmother and my grandfather are the most important people to me.* Debbie speaks of her grandmother with gentleness and fondness and her eyes light up as she recalls her childhood memories. Her recollections of that time are vivid and she begins to describe her grandmother's house, garden and the bumps in the road that were so familiar to her as a child.

> *Every time I wanted to go, it was always around summer holidays. So sure enough, my mom would put us on a bus, and my grandfather would come pick us up, and I would be so happy to be there. Every time I'd go into my grandmother's house, I'd just go running up to her and give her a big hug and a kiss. She'd always have candies for us and everything like that. It was really fun, and I loved it.*

Debbie and I planned a trip to her grandmother's home community to revisit and recall their times spent together. We are driving what seems like hours, talking the whole way only to almost miss the turn onto the gravel road turning onto the reserve. Debbie concentrates hard and begins to give me directions, slowly at first and then more readily as her memory makes sense of past locations and ways and deciphers it amidst new roads, houses and faces … *it's been a long time since I have been here …*

We somehow aim for the centre of the reserve and I remember that all roads always lead to and originate in the centre, a place where people gather or fleetingly connect, a place that never seems to be empty.

As we enter the centre we decide to stop at the band office and cultural museum first … I had called days before to ensure someone was going to be there … we make our way through long hallways and up stairs and around strange and dark corners and I can see Debbie anxiously looking around, looking for familiar faces, cousins and aunts not spoken with for a long time. She whispers ... *nobody here knows I am HIV positive* ... and I reassure her that I am just a curious friend and that telling is entirely up to her. Yet, like her I know that people will look and wonder about what it really is that brought us here together.

The museum is deserted, except for the old aboriginal man sitting by the desk, that is overflowing with paper; smoking and reading a newspaper he doesn't seems to notice us. He is not concerned with us at all ... and there is no visible sign that he remembers Debbie. While his not remembering places me at ease, Debbie continues to be on guard.

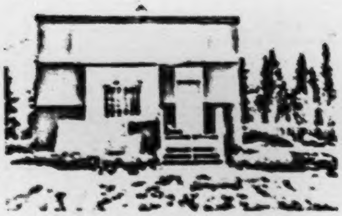
We begin to look at the beadwork, feather headdresses and more colonial tools and exhibition parts, such as stuffed animals and farming tools. There are signs everywhere reminding us not to touch anything. The room smells like dust and stuffiness and I wonder when the headdresses were worn last and when the stuffed buffalo last filled their lungs with air … we continue to walk around, looking for something we were both hoping to find … the reason for traveling this far. Suddenly our attention is drawn to the far right corner, calendar drawings of elders look at us and there we finally find a drawing of her grandmother *that looks just like her, oh my god, that's her.*

We both look at the drawing and I can see the unexpected lifting of tension and worry from Debbie's face and her high cheekbones seemed to reflect the little day light that comes from the window with greater radiance and beauty. We both wonder why this drawing was made and by whom? Before we begin to wonder out loud we look at it quietly; I now recall the feel of a soft and gentle touch, almost like a summer breeze or blanket wrapping itself around me and I knew that the hours driving with a sore back and tired eyes were all worth it. Debbie and I both wanted to touch the drawing, remove it from the wall where it was mounted onto a wooden board and attached securely … we knew that if we wanted to do this we would have to ask for help and most likely explain what had drawn us to this and not any of the other drawings … as we approached the older aboriginal man, we noticed the other younger man standing and looking at some papers scattered on another desk we had not noticed before. Debbie asked about the drawings of the elders on the wall … who drew them? When? Why? she asked gently unlike like me, her questions are well paced … the young man smiles and humbly replies that it was he who did the drawing for a calendar in honour of the elders … to celebrate their lives and birthdates. The young man kindly told us he had been wondering about Debbie, as he had recognized her. As he and Debbie reconnect and recount where they have last met she feels she can ask if there are photographs or other drawings of her grandmother. He is unsure as the museum's photographs are being reorganized, but he offers to take down the drawing from the wall and make a photocopy of it. As we follow him down the long hallways, dark corners and small doorways we meet Debbie's aunt and say "hello". We explain we are writing a book about

Debbie's life history and it is only that, that we do after all anyways … HIV is not a separate part of her life, it is part of the whole story, not outside or non-existent, just part of it. Once we get the copied drawings we return to the museum; this time the young and the old men begin to tell us about the headdresses and pipes … the cultural camps they lead in the summer time trying to rejuvenate the spirit of past, present and future generations ... they speak with pride about their work.

We finally leave the museum aware that soon everyone will know Debbie returned to the community with a stranger for a visit. It's almost lunch time and I encourage Debbie to visit her favorite cousin at the day care centre, at least for a few minutes …. It didn't take us long to find the day care centre and Debbie goes inside and I wait for some time … wondering about the community, while watching the children play and the youth return home from school for lunch … everyone seems to look at my vehicle, sometimes turning back, it is clear I am a stranger … I don't feel like I am intruding, yet it feels like it is time to leave, for now anyways. Debbie returns filled with excitement *my cousin was just so happy I stopped in and she is so excited I am pregnant and I told her you and I are doing this book and we are here to look at my grandmother's things ….*

We decide to drive around a bit; the tension and anxiety seems to have vanished, at least in the car. We feel safe that no one will overhear and ask …
Debbie suddenly gives me directions again and we begin our way out of town to the east … *there, that is*



the studio one of my songs was aired for the first time, I was so proud .... We stop and get out, take a picture and drive on ... down the road, across the intersection and continue driving. On a small hill, there is the graveyard where much of her family has been buried. There is little evidence anyone has been here in person for some time ... Debbie and I wander around, although not aimlessly ... finally she indicates over there is her grandparent's gravesite; we don't say much and I can feel the heaviness and sadness that still surrounds the loss of her grandparents so long ago.

When I lost them, it was really sad, but I know that they're in a better place. My grandmother always says, "When a person passes on and they leave you, they go to a place called 'Paradise.'" She always said that to me, so I always believed that there is a paradise.

She showed me a picture one time of this paradise ... the floors are made out of gold trimmings, marble, and gems ~ the chairs and everything are made out of all these different kinds of beautiful rocks, like rubies and stuff like that...

my grandparents

to my grandparents ~ I speak in my own way
they're there with me all the time
I feel them ~ I feel their warmth and their love and their caringness
because of my grandparents ~ I have grown up
knowing about the bible

to me God is so real
I think he is an actual person that lives on this earth with us
I thank God every day
for giving me another day to be happy

my grandmother taught me
when a person passes on and they leave you, they go to a place called paradise

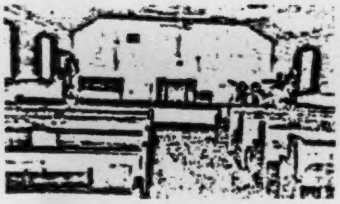
so still to this day
I believe in that
and nobody can make me believe differently

From the graveyard we go further east, down curvy roads unusual for this part of Alberta. We continue down the road for a ways and just as Debbie begins to wonder if we didn't turn too early or late, just maybe … she exclaims *there is my grandparents house, there on the little hill* ... I pull up slowly, as she knows unfamiliar peoples live in her grandparents' house now … *remember the hill and the garden I was talking about, it's just there behind the house, we used to run down there to the water. I loved spending time with my grandmother, she always used to tell us stories, stories from long ago, stories of places and people long long ago ...you know, nobody else has told me stories like that ....*

For Pueblo peoples the telling or chanting of long ago stories are part of curing ceremonies and provide protection from harm, they have the power to bring people together, particularly during times of loss and grief (Marmon Silko, 1977). I wonder if Debbie's grandmother, like the Pueblo people, knew this … Debbie's grandmother's stories, even after her death remain vivid and alive in her memory and provide comfort. Comfort lies in her memories of childhood moments spent out here amongst the curvy roads and hills …

Again we drive as Debbie wants to show me some other things … while driving she points to the scattered houses on the landscape she knows so well. Cousins, aunts, uncles some of them still live here amongst the trees and open fields, where the wind blows stories of people born long ago and people yet to be conceived.

Just as her face fills with disappointment again when she can't find the church she so often visited with her grandmother, the church comes into sight. …*it's still the same color, nothing has changed, even the grounds around the church are untouched* ... I pull up in the car beside the door, I am not deterred by the possibility of a locked door, as I know places of worship are always open, and the lock is there just to deter strangers … we enter the church and Debbie



chants …*it's still the same* ... the church, from what we can gather, is still being actively used. It is sparsely decorated with some windows covered with sheets of plywood … yet we feel the presence of something other than ourselves. We are quietly whispering to each other, afraid to leave any traces of our visit as we slowly head to the door again. For a long time we drive without talking, back through the centre of the reserve on our way home, acknowledging quietly that our visit has been important in telling Debbie's story and has help me understand … I am so glad Debbie took the time to bring parts of her memory to life for me, a stranger and friend all at the same time.

For Debbie the loss of her grandmother was accompanied with the loss of family connections to her grandmother's home community and even more so the loss of cultural and traditional knowledge.

For Debbie part of honouring her grandmother is to include her parents' and siblings' stories … since they too are part of who Debbie was, is and is becoming.

Debbie's mother distanced herself from her own mother (Debbie's grandmother) at an early age, primarily because they did not share the same spiritual beliefs. When her mother married at the age of 16 she moved away from the community, and even lived in the United States for a short while. Shortly after her marriage Debbie's mother gave birth to her oldest son and then only a year later Debbie was born.

When Debbie speaks about her mother she speaks with much hesitation and sometimes resentment. Unlike her brothers and sisters, Debbie has not remained in close contact with either of her parents over the past few years and their relationship has been strained by substance use and violence. Yet, there are still moments of tenderness and affection *I called her a couple of days ago. She was very happy to hear from me. I can tell she was relieved to hear that I was okay. Sounded like she was ready to cry, but she held back. I told her that I'm doing fine. Of course, I was happy that day.*

When Debbie grew up she was very close to her parents and her dad would often take her to places for breakfast or dinner and just spend time with her. Yet over time they *just drifted apart*. Their relationship became more severely strained when Debbie's dad reported her to Child Welfare.

The early years with her father were detrimental. Debbie knew her dad *had a very lonely life, very lonely. It was a sad life. I would have hated to grow up in an orphanage knowing that nobody cares about me. He was in jail most of the time. He never had any guidance at all from the beginning. He sort of guided himself in all the wrong ways. Took the wrong path. But he did settle down.* Debbie's father played music and traveled on several occasions when he and his children were younger. It is his adventurous spirits and his love for music that Debbie admires most, and it is through his inspirations that Debbie's love for traveling and music have grown.

The relationship with her father is different now. *We're just like two bulls. We just kind of clash. We can't really get along. We could get along, but we can't. That's kind of hard to explain. Me and my dad, sometimes we can't see eye-to-eye on a lot of things. He's the old-fashioned type. Everything he does and says is old-fashioned.*

Debbie's parents have been married for 36 years and during this time they had nine children. Although Debbie talks about all of her brothers and sisters, it is her sisters she is closest to and remains in the closest contact with.

Debbie's grandmother fostered Debbie's spiritual development, as well as a relationship with others, the land and her cultural heritage. Debbie was influenced by her grandmother's stories and beliefs, which she describes as very traditional … yet, she has lived for much of her life in different communities, including off-reserve communities and thus is familiar with the non-aboriginal ways of doing things. This tension seems to draw her back to traditional values, with desires to honour the elders' ways …

being Cree

When Debbie, Leonard and I met it was often that we would drive to make brief visits to relatives or to look after other things. I can't recall a single time where they didn't point out places on the landscape. Within these places laid stories of ancestors or events long ago and more recent. Sometimes it was hard for me to drive, as my eyes were glued to the landscape and my ears were most attentive to their stories. Spaces and places on this landscape became a large part of our conversations and they often spoke to the rupture and continuity of their culture, the historical trauma, but most of all about their own attempt to make sense of their identity.

Debbie was very proud of her heritage and had tremendous respect for her culture; however since her grandparents' death it was difficult for her to make sense and find the necessary guidance at times. *I'll always remain proud of who I am and my background — always remain proud — but I just wish there was more teachers. Yeah, I do have access to some elders but you know, surprisingly, on that reserve, they're not teachers. Like he said, they just live for themselves. They're just living the way of the world right now, that's it.*

> *There's this one gentleman, he's living in a townsite area, and he has sweats just beside his house, and this is right in the community, and all around him are drug addicts, drug dealers, alcoholics. They're all around him, and he still has sweats like that. See, those are the kind of sweats I don't want to go to, 'cause they're not sacred. The only sweats I find sacred is when a medicine man goes out and finds a sacred place and blesses it himself and gives offerings to the spirits for this area. Then that's where they belong, the sweats. When they put it up, they do it the traditional way and stuff like that. Those are the only sweats I'll go to. But they've also told me, too, and I've also heard that there are some sweats that are for people who use bad medicine. So you've got to be really careful of who you choose.*

When I go to other reserves, they're right into their traditions and their native heritage. They're constantly braiding sweetgrass or smudging, praying —

***Leonard**: Doing sweats. A lot of that stuff that goes on there in spirituality on the reserve — is non-existent.*

***Debbie**: Yeah, it is. When it's there, it's —*

***Leonard**: It's very [pause] I don't know. What do you call it? [pause] not sacred.*

***Debbie**: Not sacred.*

Debbie and Leonard talk with hesitation about their own experiences with ceremonial events, and when they do it is mixed with a feeling of sadness and loss. At other times I can sense the frustration and disappointment that so many of their own peoples have turned away from their communities and themselves.

Debbie was introduced to and learned about sweats, lodges and sundances when she was a young girl. Her late uncle was a medicine man and *we'd go in there with him and pray along with him.*

As we continue driving my eyes return to the landscape and although Debbie has not participated in sacred ceremonies since her early teen years, she recalls the powwows and rodeos as if she had attended them yesterday. *There was a lot of rodeos there. That's where we had rodeos and powwows put together, in that area. It was done up nicer than that. Of course, it's obviously old now and it's not being used any more now. But yeah, growing up, we had powwows every year there.*

The lack of teachers combined with her attendance at a high schools outside the reserve left Debbie bereft of cultural teachings and a loss of her heritage. *Ever since I went to school, high school, living in the city and meeting all different kinds of people, I just sort of left that all behind, that's a long time ago.*

Sadness enters Debbie's voice when she thinks about how she never even learned her own language … the embarrassment that she can only understand swear words … her eyes avoid mine as we talk about this, her attempt to understand why.

with sadness

I wish I knew how to speak Cree
it is really embarrassing, because when I go to
different reserves and I see little ones talking Cree,
that just blows me away
my mom knew Cree so well, but she didn't teach us

when our language went, everything else went
it's gone more the way of the world
like the world is becoming more changed in our
community
when the community changed, everything else changed
for us,
and we became part of western life

I became educated.
it was very important to me
I was very proud of it
the way I went with education is the way I went with
my life
my culture was lost
I was adapting to new things
I just became more involved in the world
just like everybody else
more in tune with everything else
rather than my own culture

the other side

Living amidst different cultures and communities as a child, and now as an adult, Debbie is constantly trying to make sense of her multiple identities and histories. She knows that there is never one way to tell or live by a story or event. Debbie's childhood years were difficult and marked by stress caused by her immediate family and the abuse she experienced from others.

But to see it happening again — like, I've never seen it for a long time, so seeing it happen again brings back memories. My parents used to do that in front of me. They don't care. They were bad, very bad. They would use weapons, and we'd see this. I don't know if I ever told you this one story. This is really bad story *about my parents, how severe it got, how severe their fighting got and their feelings for each other became just very violent. It was really, really sad. I was working at the time. I had a really good job. All my family weren't living in the house at all; it was just my mom and dad. So they were left alone to do their drinking. It came to the point where my mom was just so sick and tired of my dad's accusations and abuse that she shot him. She shot him right here. I knew that was going to happen. So me and my sister and my brother-in-law and my ex went to the house, and the doors were open. I asked the cops if we can clean the house up, since they had already completed their investigation. So once we walked in the house, we could just see the whole story. You could see it, the whole story. So all of us just cleaned it up. It didn't phase me* *or my sister, it didn't bother us, or make us upset. Her spouse and my ex were wondering why we were this way. He was saying, "If it was my parents, I'd be freaking out right now." All we said was: "Why?" If you lived in this household, you knew. You wouldn't freak out; it'd be no surprise to you. My mom just about stabbed my dad in front of us. We stopped her. So having her shoot him was [pause] a bit too extreme, but still, it was no surprise.*

My dad didn't die, in fact he was still madly in love with her. He wrote a love letter to her at the time. He wrote about him and my mom's life — in short form, but it made the prosecutors and the judge understand how he really feels about her, and being married for 35 years, having nine children together — He didn't want my mom to go away, so he wrote this letter to them *about their lives together, and how she raised — was the mother of his nine children, and they'd been married for 35 years, that's a long time, and this was all over just alcohol and misunderstanding. Yeah, so that was another traumatic experience.*

Vera: To hear these stories and to see the violence, to hear your parents fighting — how do you live?

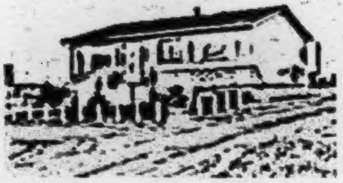
Debbie: *In fear. I don't know — I don't know; I just can't explain that part. All I can say is that [pause] it didn't happen to me, it's not my life; yes, they are my family, that's all. All I could do was just go on. I never — I don't want to — at that time, I didn't want to learn —like, you know, learn to do things like that. I just learned not to do it. I could have been a very bad person.*

Despite the close encounters with death, Debbie's parents continue to struggle with their substance use. For Debbie this has been the primary reason to distance herself from her parents. As we enter the driveway of her parents' house, at the far edge of the community, I notice the empty fields around their house and it almost appears eerie when I think about her story told just days before. It seems so terribly lonesome out here and I wonder if her parents too feel the isolation.

Debbie tries to convince her parents to seek treatment, but like so many times before her request falls on closed ears. *"Why don't you guys just both go to a rehab? Get it over and done with." 'Cause that's the biggest problem in our family, is alcohol. It's been like that for so many years, I'm just fed up.*

From what Debbie understands, her parents have never realized the full impact of their substance use on their children, such as robbing them of their childhood. I *never had a chance to be a child. I really don't know what it's like to be a child. A lot of times — well, I love kids, eh; I really do, and I just watch them play — "Did I ever do that as a kid?"*

More so however, was their inattentiveness to their children's need of support during complex and heartbreaking times. *I was about 5 and 6. I was really young. It happened before we moved out of there, away from this place. It makes me sick even looking at the picture of this place. It happened on several occasions over time. I wish I had a normal childhood like everybody else.*



> *I'd have to go way back. I think it's because I was so [long pause] sick of being so shy and closed in and mad. Just all this anger was inside of me. At times, even when I was a child, it exploded. I remember throwing tantrums, I remember screaming at my mom, swearing. That was part of the explosion, all the anger I was holding inside towards my parents. Even towards other people that didn't deserve what I had to say or what I was doing to them. Like, my friend, I used to pull her hair and push her like a bully. And I grew up just meeting the wrong people, the bad people. You know, all of us were — there was this one category. "All the bad people have to go over there; they can't talk to us good people." It was sort of — I guess deep down inside, I knew I was a better person than that, and I was sick of being mad, I was sick of being — I think it was*

shyness. The only person I've ever told was my older sister. We started talking about "Do you remember so-and-so and what they did at this time?" and she would remember, and then we'd talk about it. We had so much hatred for these people that we wanted revenge so bad, but we couldn't. We were young and we were so vulnerable. We were dominated by these people, because they were much older, we started talking about it together at first. We tried to find a way of how to tell my parents. Like, what happens to a child, they should easily come out in the first place and tell them, "Mom, this person did this to me," and whatever. But we couldn't do that because at that time, we were being put in [pause] you know "Tell your parents this, and you know what's going to happen to you next time." So I told my sister, "The only person that could *tell Mom and Dad is you." But she said no, she did not want to tell them. She says they won't believe her. She told my mom at one time; mom was putting makeup on to go to bingo, and my sister knew that she was leaving, so we felt the fear again, knowing that she's going to be gone, my dad's gone, who's going to baby-sit us again, and it's going to be this same person. My older sister told my mom, she said, "Mom, I don't want to stay home with this person. She's mean to us. She hits us." And my mom said, "Well, maybe you deserve it." That was my mom's response. That's why my sister closed herself in, shut herself away, because she didn't think my parents cared. So ever since then, she did not want to talk about it. It's sad.*

We wanted to talk to our priest that works at our reserve. So my dad phoned him, and he came down and he visited us, and came downstairs to my room, and we were talking. So to open up to somebody like that — I trusted him more than I even trusted my own parents. So I talked to him. And you know, he gave us advice. He gave us really good advice. He told us, "If you feel down and out and sad about this, or whatever, just come to the church, and we'll pray." So he was the kind of person that listened to you, a sensible person. He was such a sweet, sweet person, trustworthy; he gave me a lot of comfort. He was very comfortable to talk to. He asked us if we had a school counsellor, because obviously, this was interfering in our schooling and stuff like that. He wanted us to open up to the school counsellor. There was a counsellor that worked with

native children out on the reserve ever since we were small. So this counsellor brought us into the room, he'd bring all of us into a circle, and just go around and ask all of us how we're doing and if there's anything bothering us. But I wasn't about to bring that up in front of all the people that I knew. There was a time that I asked him if I could speak to him alone, and that never happened. He said the next time, but the next time didn't come. The next time only came when I was 15, in high school. He came to see me in high school. We talked alone in the counsellor's office. I told him. But at that time, my life was changing. I was gaining more friends rather than losing friends, so my life was sort of changing around for the better, for myself, my self-esteem. But for my sister, it was just worsening. She was getting more into the drugs. She's very secluded.

She always isolated herself away from a lot of people. The only person she'll ever be around is me, the only one she trusted was me. But I started bringing people over to meet her and sort of befriend her, but she didn't like that. I don't know if I could say she was judgmental or whatever, but she was going, "Oh, I don't like that person or whatever." She'd always have something to say about every person that she met. So I thought it was just harder for her and a little easier for me. But now that I brought that out for myself, it was just like breaking a barrier and opening it up and just [pause] starting to [pause] talk about it, getting it out, [pause] sort of releasing, relieving. That's how it felt to me. It was a big relief. I just kind of let it take me where it's taken me now. People who hear the story aren't going to hear it. I don't want to go publicize my life, either, *but if it can help somebody else, then I will talk about it. If it will also tell other people that they're not alone — because that's how I felt, that I was alone, and that none of this happened to my friends, none of this happened to my schoolmates. But who knows? You'll never know. There are a lot of people like me. I see them all over the place. When we go to the Greyhound or downtown, they're asking for money, or they are drunk or stoned. So those kind of people are still lost.*

> Whenever Debbie would talk Leonard and I would listen intently. Her talk was uninterrupted and focused … I remember the tears in my eyes and the silence that followed. It was a silence filled with emotions, wonders and puzzlement at the inaction, disbelief and most of all insensitivity and inattentiveness of her parents, the priest and the school counselor.

Debbie identified her early childhood and adolescent life stories as detrimental in her life story. A life story that includes the use of substances and aggression. It is only now after many years without using substances that she can see the connections and makes a conscious choice not to lead that kind of a life. *I have experienced it, and it's not the kind of life I want. I have two beautiful sons, and I'd never put them through that. They both worry about me a lot. They want me to live a normal life, a life that I never had.*

Debbie's wish to live a normal life meant having to revisit and make sense of her life history, life experience and in particular deal with her past abuse. She has been seeing a counselor on a regular basis and feels ready to take legal action. *A lot of people are going through a life of hell without no justice, yet justice is what a lot of people want. This is really what I want.* Debbie's voice sounds strong and determined. I wonder if she knew how difficult it might be for her to talk about her private life in public, to be interrogated, possibly dismissed and judged by others who know little about her. *I guess I'm just going to have to be brave in going on, because I have a lot of people backing me up and on my side now. They know the* *whole story. They know, and they're telling me what to do so far. And they said, "It takes a lot of guts for what you're doing." I want to do it. Guts or no guts, I'm going to do it.*

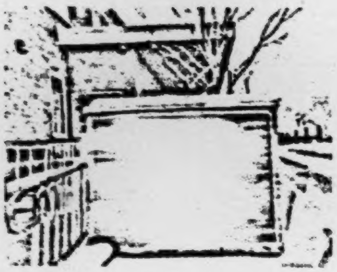
Part of Debbie's determination grew out of knowing that with her HIV positive status she could not wait to contemplate and hesitate. She needed to act while she was still feeling well and emotionally strong

Vera: Do you think with you being HIV positive, there's more of an urgency to press legal action?

Debbie: *Yes, there is. Because I believe that I wouldn't have had this if my life weren't that way in the first place. I like to say cycle, because that's what it is, it's a cycle. But I'm not going to carry on that cycle. I'm not, not to any child, not to even my own children. I won't carry on that cycle. The things that the memory left in*

> *me is very immoral, sadistic, everything. There's not really words to describe what this person has done, and I wouldn't wish that on any child. I wouldn't wish that on anybody. Yes, I did experience that very painful experience, but it's going to stop. It's going to stop. I'm going to stop it right where it began in my childhood.*

Revisiting and taking control over her own past was only the beginning for Debbie in making changes in her own life. She also had to address her substance use and find ways to cope with the challenges and opportunities that would lie ahead. Throughout all our times spent together she always talked with pride about having been able to stay away from alcohol and cocaine use.



There is a reason for everything, I know that, but for me, there is a huge reason why I had to be at that rehab and in these group session. So that kind of grabbed me, and I thought, "Okay, this is where I'm going to talk. This is where I'm going to tell them about my life. Nobody asked me a question, because whatever they wanted to ask me was already coming out. Even my counsellors were there. Everybody was completely *quiet, listening to my whole life story. Then there came the climax of my story. Nobody knew this, and I told them that I was now living with HIV and Hepatitis C, and everybody's like — you should have seen their bottom jaws drop when I finally came to the end of my story as to what my life has led me up to. A lot of people were just, like, in awe, and their minds started to wander off. I learned a lot about what I've done in the past and stuff like that. It was really. It was bad. But everything's all falling in place, everything's coming together, and if you want it to come together and you're going to make it happen, you'll make it happen.*

I find I'm doing different things that I haven't done before, which is good. I am no longer taking stuff for granted.

Debbie always had high expectations of herself and in all our conversations she rarely lost sight of her talents and abilities. Most of all, quitting drugs led Debbie to rediscover her compassion and love for others. She loved helping children both in and out of school and always listened to other's stories with such intensity and an untiring awareness. Her confidence and optimism sustained her, yet at other times she needed help and was not afraid to ask. *I can feel that I do have a lot of these qualities inside. It just takes other people to help me bring it out. I always believed in myself and what I have.*

regrets

what scares me most is letting myself go
to go back to the streets and fall into their traps

for a long time I thought this person cared
but really, they just need a person to do it with
deep down they didn't really know how i felt

I was trapped in there for a while,
taking drugs every day, taking those needles, thinking
that was the easy way

I was invincible
I thought nothing can touch me, nothing can harm me,
nothing will happen to me

but for the longest time, I was never safe –
never safe, and I thought I was

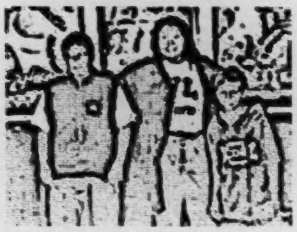
I wasn't a mother at the time ~
I was a drug abuser and I neglected my children
the more I drank the more I didn't care

I have a lot of regrets in my life
that just gives me an ugly feeling

my boys

The most dramatic impact Debbie's substance use had on her life was the apprehension of her two children. It was a heartbreaking experience for her. Talking about her boys lead us to revisit her family albums and pictures she had taken along the way.

As difficult and heartbreaking as it was Debbie realized that she was unable to look after her children while she was using substances. *I wouldn't really call myself a mother at the time, 'cause I wasn't a mother at the time. I was a drug abuser. I neglected my children. I don't know; I guess I kind of fell because it was so stressful just staying up there and just hanging in there, being the single parent with two children, that I just broke and I couldn't take it any more. My parents didn't want to help me any more, my family didn't want to come around because they knew what was happening. My dad got really sick and tired of what I was doing, so he called Child Welfare and got my two boys taken away. So I struggled from there. Nothing was helping me at the time — nothing. Not even dealing with social workers and foster mothers. That was* *just kind of adding to the stress that I was going — and the frustration that I was going through. My whole life, I can honestly say, was just going downhill, really fast. Every day was just a bad day for me. It was just getting worse and worse every day. Every day that came got worse and worse. I got more heavily into using substances, and the more I did it, the more I didn't care. The more I drank, the more I didn't care. So they got taken away. I know it was heartbreaking for all of us when we all parted, and they had to go, and I stayed behind. That made me really angry to see them take my boys away. But I thought about it, too, and thought, "It's going to help all of us out." But at that time, I didn't know how it was going to help, but it did. Eventually, everything fell in place. It eventually did help. Now my boys are really happy.*



Despite being able to stop the substance use and seek continued counseling, Debbie has not had her boys returned to her, which continues to be a source of frustration, anxiety and uncertainty. However, her children come and visit her and she often talks with them on the telephone. The deep love and affection for her children was present throughout all our conversations. Debbie knew she still was struggling sometimes but was determined to fight to have her children returned to her.

But now when I see them, they're more stronger than ever. I just have so much faith in them. They're happy kids, they love their friends, their school, everything, their new-found structure in life. They miss me a lot, and one of these days, they know that they're going to come back to me. So when they do, I just hope I do a very good job. I know I will. Sometimes I just say these things because of my mistakes from before, but I have a lot of faith in myself. Now that I quit everything I think a lot of things really changed for me, especially when I have them back. So I'm looking forward to that.

Coming to terms with the virus

Struggling to cope with the apprehension of her children was extraordinarily difficult and challenging. After her children were removed from her care Debbie continued to use substance to cope. Despite her substance use and chaotic life Debbie always managed to go for routine HIV screenings on a yearly basis. *So it was just that year was my time to do it again, so I did it. But that last test, I kind of thought something was wrong, because 3 months before that, I had a really bad flu, and I've never been that sick. I've never been that sick in my life, and this was so bad. I was bedridden for 7 days.* About three years ago now Debbie was diagnosed as being HIV positive *and when I got this, everything just kind of crumbled on me, and I just felt, "I don't have it any more."*

when I first found out

I was totally, totally devastated, hurt
I thought it was the end of my life
I thought I wouldn't be living very long
I was really distraught at the time
I just felt ashamed of myself
I felt really unworthy
all these feelings of worthlessness
it was like a heavy burden
I fell into a depression
I felt worthless and useless

I was an emotional wreck
everything just crumbled on me
I felt alone

Expert
the Champ
Car Wash

Although Debbie was injecting at the time she always used clean needles. However, as she found out later, her ex-boyfriend was sharing needles with many people.

Right from the start Debbie's doctor told her how long and how well she would live with the HIV virus was dependent on how she looked after herself. Whenever we talk about her HIV positive diagnosis Debbie remains calm, but I can see the anguish and hurt still passing over her face when she remembers the time when she was first diagnosed.

Debbie has been open about her HIV positive diagnosis and has experienced a number of different responses to her diagnosis. *My dad, he was very mad when he first found out I was sick. He didn't want to ask about it, he didn't want to talk about it, but he knows about it and he knows what it can do. He still talked to me, he still suggested things to me. He still says, "I love you," stuff like that.*

It's different from my mom. She doesn't know much about HIV or AIDS and thinks otherwise. You would think that my dad would — maybe he would explain it to her. I'm not sure. She was stuck in some ways, because she thought that you get it from sweat and kisses — I don't know where she got that, but it's not that way, that's what hurts me the most, because you can't.

All my other relationships with my sisters and brothers stayed the same. None of them look at me different, none of them condemn me for it. Nobody really asks any questions, just my youngest sister, she wants to learn more. My sister surprised me. She wanted to taste the pop we bought this one time — it was a strange, weird pop, but she wanted to taste it, and she took my cup. She was telling me earlier that she was afraid of HIV, but she sure wasn't afraid of it when she took my cup. That was after I told her about it. It makes me feel good that they know. I'm really glad for that.

For Debbie, her HIV positive diagnosis didn't really change any of her close friendships, at least from what she knows about the people she still stays in contact with. *They're not so judgmental about it. They don't see me as that. They still see me as me, Debbie.*

Although Debbie's friends and her family, with the exception of her mother, were supportive and did not alienate her, she felt a strong need to talk to other people who are living with HIV. *I had a friend of mine ask me, "What would you do if this girl came crying to you, and she just found out she had AIDS, and she put all the pressure on you?" "What is pressure? What do you mean pressure?" "Just pressure, like crying and wanting you to help her with it." I said, "I can't take the virus away, but I could sit there and talk*

> *to her about my experience and how I felt about it. The best thing I can do is just what you're telling me, is other people would like to hear that story and ask themselves questions, "What did she do when this happened? How did she feel when it started happening?" I would be open to a person like that, because I know how it feels when you first find out. I had nobody at first, but I knew one person who was living with the virus as well. I needed so badly to talk with this person because I didn't know who else had it, I didn't even know. My sister told me about all these community agencies. But do you think I would go there? NO!*

Although conversations with friends and family reassured Debbie and helped her make sense of her life, it was not the same for the responses she received from community members. *We just hear bits and pieces of rumours and such. People pointing, "She's got HIV," stuff like that. And I believe the people that are pointing at us are the people that also have it, because there's a lot of people in the community that do have it. They just don't want you to know. A lot of people are like that, very judgmental people, they stereotype others. It's really sad. We don't really associate — we only associate with our families. We're in and out all the time. But like I said, if people have something to say about it, they can come and ask us; we'll tell them. They don't have to go and whisper behind our backs.*

That's not fair or that's not nice at all. We try not to let this hurt us, because to us it's their problem if they can't understand or accept it.

For Debbie the combined stress of losing her children to Child Welfare and her positive diagnosis of HIV added up and as a result she has battled depression for some time now. Her initial bout of depression was accompanied by terrifying emotions, and she was haunted by bad dreams. Debbie had experienced mild forms of depression before, but not like this one. It seemed to have robbed her of all her emotional, physical, spiritual and psychological energy. The depression seemed to take over Debbie's life without mercy or compassion and it took Debbie some time to finding meaning in her life again.

I don't want people to come up to me and visit me and I'm in bed and I'm sick or whatever. I still want to live that normal, happy life.I guess the acceptance part came a little later on. It took me about a year and a half to accept that, make that decision: "Now you have to turn your life around." That's the sad thing, when people don't turn their lives around, especially when they have children. The children need them the most. I always, always thought of my children first, and the people that are in my life that really love me. People that I love always come first. So, like I said, I would never want to cheat them out of loving me or being with me. I'm really proud of my boys, I changed mainly for myself and the new baby that's on the way, and especially for the boys. I want to live as long as I can with this. I want to be as happy as long as I can, living

> *with this. I don't want to be depressed. It's not going to get me anywhere. So far, I feel [pause] I feel great. I always thank the Lord every day that I'm alive, for giving me another day to be happy and to enjoy my family and to enjoy people that are around me. I thank God every day for that. I say my prayers every night. I especially pray for my two boys who are doing really well now. They have been very educated on HIV, and they know everything on it now. It put them more at ease knowing that it's just the virus. Yes, it can turn into AIDS if you don't take care of it properly. They know that.*

To date, some studies have focused on the experiences or specific needs of women living with HIV/AIDS (DeMarco, Miller, Patsdaughter, Chisholm, & Grindel, 1998). In health related literature, women living with HIV/AIDS have primarily been perceived as possible sources of infection for their children and male sexual partners, rather than as individuals who are infected themselves (Gillespie, 1995). This is apparent in the discourse around HIV/AIDS whereby women are seen as 'vectors', 'reservoirs' and 'carriers'. Yet, becoming infected with HIV/AIDS affects every aspect of women's lives. Women infected with HIV/AIDS grieve for the loss of their health, loss of hopes and dreams for their future, loss of feeling physically desirable, loss of their unborn child, loss of financial security, and they often grieve the loss of friends, lovers, partners and children who already have died (Wiener, 1991). The diagnosis of HIV/AIDS leads women to re-evaluate their sense of self and life as they know it, and they often have to make a conscious effort to take control of their life again (DeMarco at al., 1998).

Things have changed for Debbie now. *But I held in there, 'cause I was much stronger than that. I always told myself I was stronger than them. "Why am I crying about it? I'm stronger than this." I know it's in the blood. And you know what? You know how much I praised my grandmother? I think she's watching over me. I think she's the one that's making me as powerful as she is. My real grandmother, she was a very strong woman*

Like now HIV is really nothing. I think. It's really nothing 'cause you don't feel the pain that people go through when they have cancer. You don't feel as scared as they feel, knowing that it is growing inside of them rapidly, and their lives are going to be shortened within days or months or whatever, when God decides *to take them. I don't really think that my life has really changed in a big way. I feel still the same.*

Women's social well being is not only influenced by the fear of abandonment or rejection, but also by concern about their family, their disease progression, and their financial situation. Women not only worry about their own lives, but the lives of their partners, families and in particular the lives of their children. Frequently women with HIV will forego their own health needs to care for family members who may or may not be HIV positive (Jackson, 1997). While children are a source of concern for mothers living with HIV/AIDS, they are also a source of strength (Dominguez, 1996). Sharts-Hopko, Regan-Kubinski, Lincoln, & Heverly (1996) emphasized that HIV/AIDS is a disease that affects the entire family. The effect of women living with HIV/AIDS on their family and particularly their children has not yet been researched.

But after all “mothers’ stories and children’s stories are always intertwined: only theory can try to keep them comfortably separate” (Hirsch, 1997, p.165).

Frequently mothers diagnosed with HIV need their children for emotional support, practical support and most of all motivation to continue their life and make sense of it (Van Loon, 2000).

Women are the fastest growing population living with HIV in Canada as well as internationally (McDonnell & Kessenich, 2000; World Health Organization, 1992). Moreover, a disproportionate number of aboriginal women are infected with HIV (HIV/AIDS EpiUpdate, 1998). The number of aboriginal peoples with Acquired Immunodeficiency Syndrome (AIDS) in Canada has increased from two percent prior to 1989 to more than 10 percent in 1996/1997 (HIV/AIDS EpiUpdate, 1998) and in 1999 they accounted for 15 percent of the cases (HIV/AIDS EpiUpdate, 2000). Anecdotal information suggests that the number of aboriginal peoples with AIDS in Canada may yet be higher (Matiation, 1999a; McLeod, 1997). It has become clear that HIV/AIDS does not occur uniformly across ethnic and racial boundaries.

It is important to note that HIV prevalence data has come primarily from studies involving aboriginal populations living in urban areas or in mixed populations where aboriginal status is identified. Therefore, these results cannot be generalized to the aboriginal population living on reserves or in rural communities. Furthermore, these studies do not adequately capture the individuals who migrate between communities and urban centres (University of Manitoba, Northern Health Research Unit, 1998).

Aboriginal peoples are at increased risk for HIV infection for several reasons. Higher rates of sexually transmitted diseases (five to ten times the national average), higher rates of substance abuse (including injection drug use), and over-representation in federal and provincial prisons as well as other health and social issues increase the vulnerability of aboriginal people to HIV infection ("HIV/AIDS research priorities among aboriginal people in Canada", 1999). A disproportionate number of aboriginal peoples utilize inner city services such as needle exchanges and counselling programs. As well, aboriginal women are found in increasing numbers at clinics caring for HIV infected pregnant women (University of Manitoba, Northern Health Research Unit, 1998). The transient movement of aboriginal peoples from inner cities to reserves and rural aboriginal communities brings HIV to even the most remote communities.

Of the 332 aboriginal AIDS cases reported to the Canadian Laboratory Centre for Disease Control (LCDC) by the end of 1997, exposure categories for 213 men and 42 women were identified. Among the 42 aboriginal women infected with AIDS, 47.6 percent reported injecting intravenous drugs as the source of infection, 35.7 percent had heterosexual contact, and 9.5 percent received blood/clotting factors (Laboratory Centre for Disease Control, 1998). Although women are at risk for infection from the same sources as men, they can also be the source of the virus for the fetus through the placenta and by breast feeding (Pinch, 1994).

I don't even want to go on medication myself, but I know that it's going to stretch my life a little bit more, rather than just living like this and having a short painful life and dying. There's a lot of things that I have to live for, and a lot of things that I want to live for. Knowing that I have this is reality to me. I know. I've accepted it now, and there's just a lot of things that I have to do about it now. I've changed my whole lifestyle, I've changed everything. I've stopped everything going into my system, especially drugs and alcohol. That was always, always my biggest fault in life; it was my biggest fault. And I thought to myself, "You know, no matter how I feel about this, I can feel as depressed as I want, what I have to stop and think, I really do love my two boys. I really do. And the man in my life, I love.

Falling in love

Relationships shift in multiple ways when people become infected with HIV. At times they make those infected acutely aware of their invisibility when they contract the disease and add to the continued oppression and marginalization of those affected by

HIV. At other times they provide strength, hope, and meaning to their lives. Debbie was diagnosed as HIV positive about two to three months into her relationship with Leonard. Debbie was amazed Leonard did not give up on their relationship and in fact has become her primary source of support. *I noticed a lot of my family, now that they know, they look at him like, "Is he ever brave! He's brave, he's strong. What kind of guy would stick around with someone who finds out they have it?" Only he can explain that. I couldn't explain that. I can't. I told him, to me, if I was a totally healthy person and I found out my new spouse has gotten it, I would be scared, to tell the truth. I would be really scared, and I probably would just remain friends. I'd be a coward, because I'd be scared.*

falling in love

what kind of guy would stick around
with someone who finds out they have it?

after all the doctors said that I am committing
suicide or something, but I don't see it that way at all

you fall in love with somebody, you know
it's unfortunate that she got sick, and myself, too,
but that hasn't changed my love for her
she is a person, and that illness she has, is just an
illness, you know
that's the way I see it
I never chose to love her to die
I chose to love her to love her, to be with her
we fell in love, we feel strongly about each other

he just chose to be with me and to love me and to stay
with me

it's not why me,
it's just, simply, we fell in love,
we feel strongly for each other,
we connect in almost every aspect
I don't feel any different, still to this day
in fact, I think we're even stronger

Sometime after Debbie's diagnosis Leonard was diagnosed as being HIV positive as well. *It hit me hard, but I didn't want to show it to him. I didn't want to take it out on him. I didn't want to blame anybody for anything. I was seeing a psychologist at the time, because it was really devastating to me, knowing that. To tell the truth, I felt like a murderer. I haven't murdered anybody in my life, and somebody that I love dearly, with all my heart — I felt like that. But he's with me; he's with me. He's not dead. I felt, again, ashamed, that this had to happen to him. We both have children, and that's the main thing I was really thinking about, too. It was the future, and his future with his children, and my future with my children. That was thought about a long time ago, but coming to terms with what he had,* *it was hard for me, really hard. Yeah, I did talk to him about it, I opened up to him about it, but I couldn't really explain, because I broke down right away. So I watched myself. I should choose a right time and a day when I could explain this to him, but I had to tell him that day because — I didn't feel forced or anything, I just felt kind of obligated towards my psychologist, that she wanted to know what his reaction was the next day, so I did choose a day and opened up to him. Still, I couldn't explain it to him properly, you know, but it came out. He knows. He knows that I felt awful about it. and awful is not even the word.*

Her relationship with Leonard was critical for Debbie. At the time I met them they were still deeply in love and were not afraid to show the affection they held for each other openly. For Leonard the relationship with Debbie helped him cope with his diagnosis. *He told me — I don't remember the exact words, but in a sense he told me that — he goes, "I'm glad that I'm with you, and that we're together, and that we're both going through this together, because you've already experienced the worst of it all, and now it's my turn, and I'm glad that you're with me to go through this with me," because he doesn't want to be alone.*

Despite the strain their HIV positive diagnosis placed on both of them, as well as their relationship,

they never forgot that in order to survive laughter and joy had to remain a part of their lives.

Making sense of relationships and experiences is difficult at the best of times and even more so in times of uncertainty and loss.

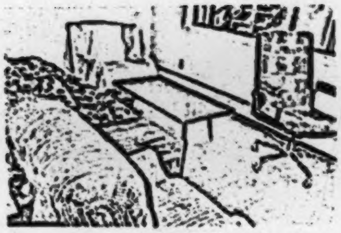
Debbie and Leonard were used to living in the city; the first time I met them they were in the process of moving from the small community where they were living with Debbie's sister, back to the city. Despite the threat that they may be without shelter of their own they chose to return to the city. *It was quite a good change, and it was, I think, a little better, because being in the city, you feel free to do whatever you want, you can go anywhere, do whatever. Out there, you can't. You can't just go outside the house and do whatever you want, because there's nothing to do, unless you want to go climb trees, and that's all you get, or walk down the* *road.*

After several weeks of looking for stable housing Debbie and Leonard grew increasingly anxious and were worried about locating shelter at all. Being homeless had drained them of financial, personal and emotional resources. *Right now, I just want to find a place, just to start stabilizing myself in that way. 'Cause right now, I feel so up in the air that I feel so lost. Not lost to the point where I don't know what I'm doing, but lost because I don't have a home. I could easily walk out on the street and say, "When night comes, where do I go?" That kind of lost. Pretty soon, I'll be running out of those resources. Hopefully by the end of this week. I really want to try for this week.*

Due to their constant homelessness resources were frequently difficult to access. *Yeah, but we do have to send in a reporting card stating where we live. So now we don't have an address right now, so we're going to have to wait until we do get an address, and then send the reporting card. That's going to be hard. If Capital Housing doesn't come through for us, we're going to have to look in other places, other ways to get an address. Otherwise, they'll hold the cheque. Yeah, but I can't use my friend's address any more. I'm just too scared. I just needed that help for one month. So we're on our own now, and we'll have to get our own address. So hopefully, we can get it before the end of the month. Then we won't be stuck for money the next month. Especially for December. I'm not really looking forward to Christmas.*

***Leonard**: No. We got to find a place, 'cause we're going to get a hamper for Christmas, too.*

a new life



It was just before Christmas that Debbie and Leonard did find a place. Through different services providers they managed to locate furniture and dishes. Needless to say, the relief that came with finding a shelter was tremendous.

Throughout all her time of being homeless and without access to numerous resources Debbie was pregnant. *So anyways, like I said, when I first found out I was pregnant, a lot of things just went through my head, and I was a little overwhelmed, very scared. I was literally shaking, knowing that I had another life inside of me when I have this disease, and it was a real scary thing. It was a real scary thought knowing, "Oh, my God, my child is going to have this." That's all that went through my head.*

For Leonard the child became almost like a blessing in disguise. *The baby also changed our mental state at the time, 'cause we were totally depressed. Utterly. Although I still get depressive now and then, it's just because of the illness, and I told her that. It's a difference having to know that we're going to bring a baby in the world. Being together, bringing this baby. Hopefully, the baby will be healthy, but she's doing all the things already that — she's already taken those steps to take care of herself in order to take care of the baby. Soon as that happened, everything — our sleeping patterns changed, our mental outlook was a little better. Even physically, you know.*

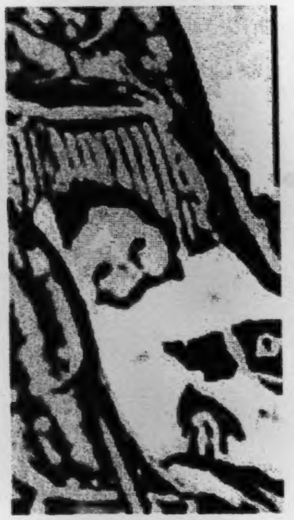
As soon as Debbie found out she was pregnant she realized that she needed to seek medical attention. However, seeking medical help was not without mixed emotions and difficult decisions to make. *Right now, I know that I would feel devastated, thinking of the thought of giving my child medication right from birth. I was scared at first, because all these things just went through my head: "Oh, my God, the baby is gonna be sick." But I don't want to look at it that way. You don't even know if it's going to be sick yet. I'm just saying I thought, "Okay, I have to take these medications to decrease the risk for the baby of getting the virus." They gave me this paper to read about the side effects and that, and that's what scared me. I thought, "Maybe I should take an extra day to think about this." I was reading this paper alone in the room, and I just threw it* *down. I got so scared of the medication that I started crying. I started crying because it scared me, the side effects. Leonard come in the room and he started holding me, and he was trying to encourage me and trying to ease my mind about this medication. He said, "Look at all the other drugs you used to take; look at the side effects those had." Those drugs that I took were worse than the drug I was supposed to be taking now. I didn't think about that! [laughs] But he told me this, eh, and it was true; all the other drugs I used to take were very harmful. So I thought, "Okay," I chose a time, 11 o'clock — "11 o'clock is the time I start taking these pills." So I did. At 11 o'clock, I just told myself I'd start taking them, because if there's any side effects, I was telling myself my doctor had told me to call back and they'll change them or whatever. So I took them for* *the first time, and nothing happened; I was okay. I went to sleep. Took them in the morning — that was the morning, and then we went for a walk. Nothing. I never felt not one side effect. Before I took them, I said a little prayer. I was also talking to my grandparents maybe that's why I'm alive, because they want me to go through this, because it is my disease I have, to bring this child into the world. Starting was the hardest. I knew deep down inside I wanted to do this, but I had to do this for the baby's health. I was not going to risk it.*

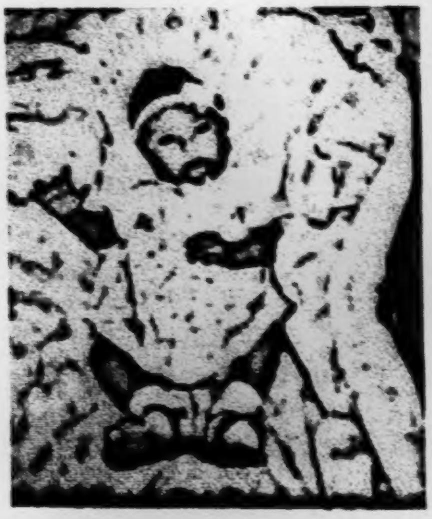
Amidst all these worries, Debbie and Leonard experienced the joys and anticipations of pregnancy. *That is a happy thing for us, knowing that we are bringing in a new life. A lot of times, I think, "How's this baby going to look? More like me now, or like him?" Because my other two children look like* *their father. Everybody says I have weak genes — they don't really look like me. I could see the strongness in his. I can see it, so I'm just trying to combine the two together sometimes. It's exciting. I haven't been pregnant in a long time. It is like a new experience for me, all over again. The heartbeat of the baby was very strong. I was really surprised, because the first time, you know we could barely hear it. She said that maybe it's still too small. But when she found it, it was so loud and so strong, that she just started laughing. She just felt that excitement with me! [laughs] "Wow, this is so neat!" I haven't had a child for 9 years — going on 9 years — so this is like a beginning; it's exciting. I love it. Like everybody says, it is a blessing, I believe.*

It was just before seven in the morning when I noticed the message on my answering machine … Debbie and Leonard were on their way to the hospital … I guess the baby just couldn't wait any longer …. I got there just a few minutes before they did and waited in the hallway wondering about what might lie ahead in those next few hours … as a nurse, a woman and a friend I wondered …. Debbie so often referred to this child as her miracle baby who grew out of deep affection and love … her body knew what it meant to be in labour and to anticipate pain and agony and I wondered how she would cope this time … the worry that the baby was going to be OK … that the pains would be attended to quickly and without hesitation … I wondered if Debbie and Leonard were prepared for

this … a new life … long imagined and dreamed of …

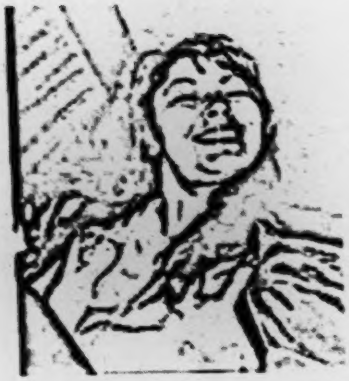
long before even born or conceived …





dreams

My dream is to have my family together with me, supporting me through my music. But those are goals that really can be met, and it's going to happen. I have a lot of faith in it. You just got to make it happen, and I'm going to make it happen. So far, I've gotten and pushed aside the most worst thing of all, with the alcohol and drug abuse. That's where most of my depression came from. So that's also subsided. I like that, because I feel normal now. I feel more focused every day.



there are lot of things that I have to live for

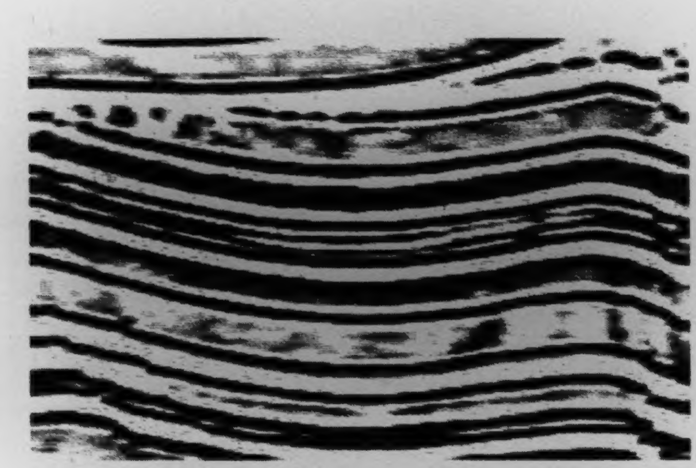
and a lot of things I want to live for

I want to live as long as I can with this

I want to be as happy as long as I can

I still want to live that normal happy life

this is my story and I am sticking to it

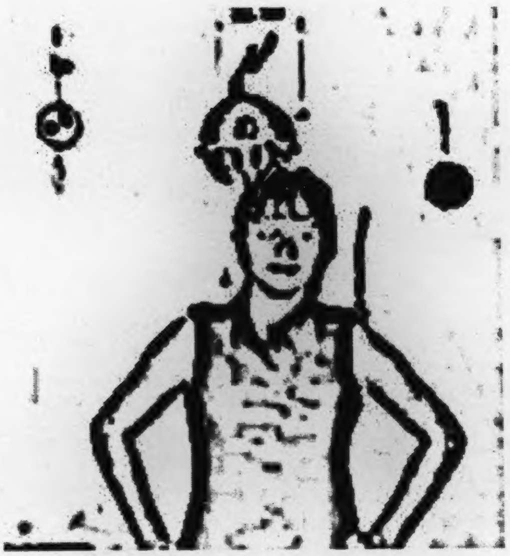


Tammy in relation with Vera Caine

August, 2002

Living with HIV:
It's not about dying.
You're not going to die the next day,
you're not going to die the next year.
Take care of yourself, live your life.
At least you'll have had something before you die,
instead of feeling sorry for yourself.

Tammy, September 2001



this is my story and i am sticking to it

acknowledgment

a letter to my mother

remembering my mother

when my mother was still alive

some (m)other stories

without my mother or who am I?

reclaiming motherhood

and then some more

tribute to my family

acknowledgements

This book is dedicated to my family: my daughters C., K. L., and J. T.; my brothers; my dad and extended family; and it is for you mom.

This book is also to all the people who are living with HIV. The stories are told so people can understand that living with HIV is not a death sentence but a life sentence. The stories are intended to show how we can survive and live and love and to not feel alienated. Everything in life happens for a reason and we will find out down the road ... I strongly believe that the creator did this for a reason, that HIV is something we can learn from and maybe to help us see what we are doing to ourselves. Just don't forget that the creator will always be here for us.

This book is not only for people living with HIV, but also for others to let them know that we are not any different .... This book is just how I feel and what I went through and I hope this will give you some faith and encouragement

Hai Hai

a letter to my mother

dear mom;

today I was thinking about you and I really want you to know how much I love you and miss you. I want you to know how much of a good mother you were because I do remember when we were kids and no matter what happened if we were bad or good we all knew how much we meant to you and for that I am thankful. And I do remember that when we got taken from you, no matter what, you always got us back. At the time, well, I did not know how much that would take from you; but now I do know and mom you were one of the best. I wish I could have told you this before you left us to go to that beautiful peaceful place. I know that it was hard for you to leave us, but mom I do know that you were suffering and you were tired. Mom I do hope that you can forgive me: I'm sorry for the things I did to you and against you but at the time I was under the influence and did not know what I was doing. Mom I wish I had what you had. I'm talking about my *children: you always got us back, but when I had my babies I didn't know what to do. The drugs had their grip on me and I wish it could have been different. This letter is to you and I just want you to know that I love you and miss you and to let you know that the drugs don't have a hold on me anymore. I wish I could have done it with you by my side and that you were the best and I'm sorry. But even if you are not with us I still want you to know what I have done with myself and my life. Well mom, I do have some good news for you, I did get engaged and I do have two beautiful little step daughters and a wonderful man by my side and I know that you would approve. And also I got to learn about my culture and that is where I got a lot of strength from and it taught me that you don't need something to take away the pain, because all you need is to find that spirit with in yourself. And about the children I will try and be the best that I can be and use what I should have used a long time ago my motherly love - just like you did when we were kids and also to let you know that I am trying to do what I said I would do. About* *the last time mom I wrote you a letter, just know it was very hard. All I could do was think of you and how hard you tried when we were kids and I am trying to keep your baby by my side, but I can’t tell him what to do. I wish I could, but he is ok. About my big brother, we have not been getting along, but mom you taught us that family is more important than anything and I am going to hang on to that - I just hope that he does too. Don’t worry about us because I guess I could say that we are all growing up, I know it took a long time, but we are getting the hang of it. I have to say about myself that for a long time I was blaming myself for what happened to our family but now I know different. All I know is that I love you and miss you, we all do. I am going to do my best, I am sorry for our past. I LOVE YOU AND I MISS YOU and I know that you are looking after us*

… …

with love, Tammy

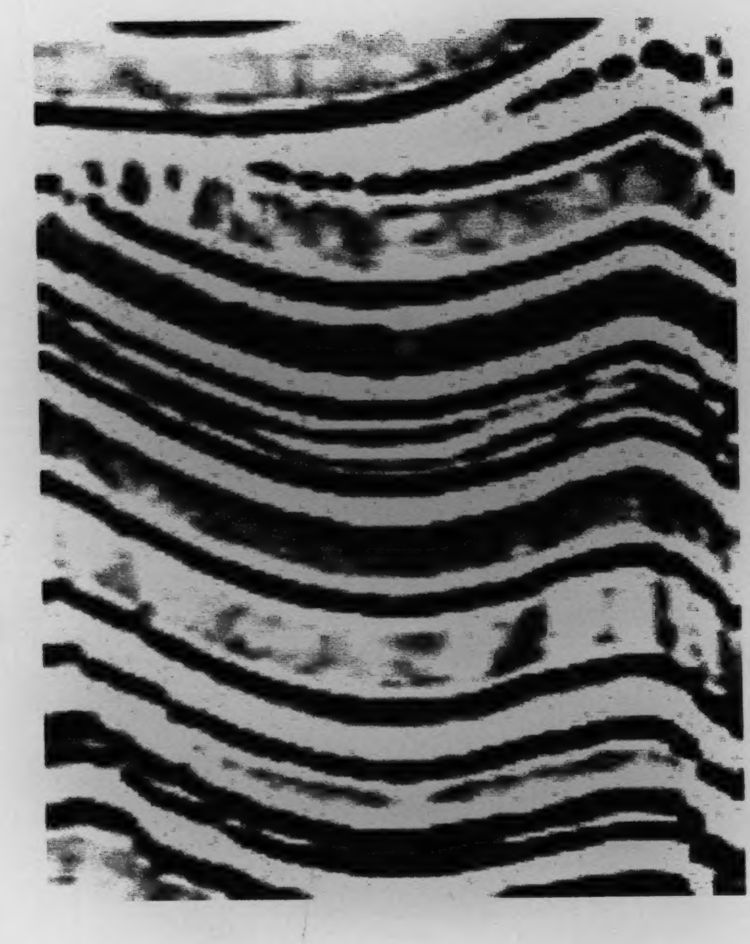
(   )

remembering my mother

This is my beautiful mother, who gave birth to me and my brothers. The picture was taken when she was about 31 and before she got sick. She was a very good mother. She was a Cree women and was born on a reserve near the Alberta border. There is lots I don't remember because of the drug use, but the thing I do remember is that she loved me and my brothers. Before she was into drugs she was the best. She was very unique: she had a sense of humor and she was a strong women. She *got sick with kidney failure and at that time we all became confused and started using drugs. Prior to this we were not into drugs, instead we were a really close family. However, my mom ended up in the hospital and when she returned home she started to use drugs; at the time it was to kill the pain. At the same time I went to Vancouver for a while and when I got back I saw her injecting Talwin® and Ritalin®. I hated the thought of my mom doing needles and that is how I became addicted. I don't blame anyone but my self.*

My mother was so cute. She was just so very important. I remember this one Christmas when we all got everything we all wanted. She made it happen. Even so we were poor, we had love and she always let us know always how much she loved us. Even if we had no money she always got us what we wanted. And I remember this one time when there was this show on the tube and there was all of us: me, my brothers and mom and my cousin and her boyfriend and we played this game. We all had to do sit ups every commercial to see who did the most. I don't remember who won but that was one of the things I could remember.

Looking at the photograph that shows the large, colourful blanket that covers the window of Tammy's living room marks the beginning of our conversation about Tammy's mother. A blanket that once belonged to her mother. The blanket embodies the birth and protection her mother offered. A visual symbol of Tammy's identity and pride, her relationship with her mother, her past and a time where life was somewhat more predictable.



when my mother was still alive

I love you my girl

the relationship between mothers and daughter .. filled with such tenderness and concern … as the tears stream down her face, who will be there to comfort her? her mother? her brothers? … ?

My mother tried to be there for me and not treat me differently and love me more…but we were into drugs and the communication was harder and got harder, but the love was always there …

the experience of unconditional love, love without beginning or end

My moosimim and my kookum from my mom's side are both native. My grandmother from my dad's side is pure French. That's why I got so white, 'cause my dad and all my aunties and uncles are all dark. So are my brothers; they're dark and they tell me they found me on the doorstep, eh! [laughs] 'Cause I'm so white, eh. [laughs] So I think that's where I got the white skin from, from my grandmother. She's pure French,. I don't even know what my dad's cultural background is, you know that. I think that my dad's Cree. I've never met my grandfather. I've only met my grandmother. My mother's family is from a reserve close to the Alberta border, but I have never been there. I think my brothers have. Well my brothers have been everywhere, you know, being young, stealing cars and going everywhere. Me, I never got into stealing cars or nothing.

I don't remember much about my dad, he was never around when we grew up. I don't even have a picture of him. After I turned 14 he came back. He came to see me, and I was so weak and out of it. He came to my dope house. I opened the door, and I was all *messed up. "Dad, uh [pause] uh." And I didn't know what to say to him. You know? and I asked him if he wanted a fix, which he did. Then after he did it, he was gone. Like [laughs] I think he got too high into the drugs. But he doesn't do drugs no more 'cause they're bad, and he doesn't drink, and I guess — I guess he works now — some kind of work with the government.*

Okay, this is how it went. Growing up, we were always a close family: me, my mom, my brothers, and my aunt and her kids. My mom used to drink, right, and she lost us a couple of times, but as soon as she did, she got us back right away. Like, she straightened out right away and got us back. She was a really good mother. Then when I was 12 — no, about 11, she started getting sick. My youngest brother was about 7 or 8, and my oldest brother was 14. Then when I was about12 years old, that's when hell started and it all went down.

One day, my brother had came home with two of his friends, one of his friends, and his friend's friends. My mom was sick by then. She had kidney failures, and she bloated everywhere. We had the thing — the IV thing — at home. Out of the blue, one of the guys that came to our house with my older brother pushed my mom down the stairs. I got really scared. I said, "Look what he did to Mom!" I don't know where the knife — like, my brother used to be a Ninja, eh. He studied everything, and he had a Ninja knife. I *don't know where it came from, but it came. I turned around, and he was stabbing that guy, like, 'cause he hurt his mom. He was 16 at the time. The guy who didn't push my mom, after that, he died. The guy who did push my mom, didn't. So when that guy went staggering out to the back, I went and followed him. I was 12 years old, right, and he was on the stairs, bleeding, and I heard him barely breathing, and I went upstairs. "He's barely breathing!" I was crying. My older brother went downstairs to check on him. Like, he didn't know, like, what happened, but it was out of protection of his family, right? And he came back upstairs, and he was crying, and he said, "He's dead." So his old lady wiped the knife. She shouldn't have did that. We called the cops and everything. They took him and he came home for a bit, but then he went to trial and got 5 years. After he went to jail, I was the oldest.*

After that, I was the oldest and I did what I wanted. I was like -. My cousin reminded me the other day. She said when I was 13, I guess, they came over to pick me up, and I told her, "I can do what I want. I'm the oldest now," and I guess she slapped me. I don't remember, though. You know, I seriously don't remember my childhood — just the bad parts, and maybe some good parts, but the rest —. Like, I see pictures of me and my cousins and that, and I don't remember it. I don't know. I think maybe all the dope I did and stuff, is why I forget.

Well, once my mom started getting sick, actually, my mom went to the hospital and she was in the hospital for over a year. I was in school at the time and I used to go visit her every day. Then things got hard and I went to stay with my dad in Vancouver. So, I went to Vancouver and I didn't start drugs there. I didn't. I hated cocaine. I've never tried it. I hated it, 'cause my boyfriend asked me if I wanted some once, and I just looked at him like he was nothing. I was like that, eh. I went to Vancouver, and I was living with my dad for, like, a month, and I missed my mom, so I came back. When I came back, my mom was injecting Talwin® and Ritalin®, and I couldn't handle seeing her doing the needles. So this girl came in, this other hooker came in, and said, "I don't do coke. Do you want this?" I said, "Yeah." I was 14 years old at the time. My mom looked at me, and she said, "No, my girl, no!" and I said, "Why?" You know, if you can do it, I can do it. I thought if I did it, she would quit, and then, that would be it, but instead, I got hooked.

Once I came back I looked after my mom, I lived with her off and on. Or I would just go and see her, or if I would get cleaned up for whatever, I'd go find her and try and take her home. Oh, there's a lot of bad memories of the drug life, because she overdosed on me so many times. Like, for the longest time, I keep thinking something's going to happen.

Even before my mother got sick, I was already smoking pot and [long pause] I guess I could say I was drinking. I was drinking and smoking pot and stuff. I started to smoke when I was about 8. Drinking, about 12, I think. It did it just [pause] to get high. But, after my mom got sick I started using cocaine. By the time I was 16 everybody downtown knew me, most people called me baby, it seemed everybody looked after me. I always had rigs, water and supplies, always enough for everybody. I use to sell drugs, before I started working the street. I didn't work the streets until I was about 18 ... my first time I did that, I felt so low, and then after that, that was nothing ...

my first time I did that, I felt so low,
and then after that, that was nothing

For the longest time, every time I tried straighten out, it was always for my kids and getting them back. My mom came and found me one day, and she cried to me, and she said, "Quit using drugs, my girl. Your baby is so beautiful. She's got green eyes." And I swore at my mom. I said, "I can't handle this right now, Mom."

If I would have — sometimes I think if I would have listened to her, she'd be alive today and I'd have my baby, you know. Every time I wanted to straighten out I did for my babies, but it never worked. So I had to change that. If I kept holding on to that I wouldn't be here today, I wouldn't be straight. I had to change for myself first. My oldest two daughters, who are gone, they've been gone for so long. At the time, I was, like, "They're gone." I drowned myself — I was in my drugs. Not any more, though, because if I were to keep doing that, I wouldn't be here.

Now I sometimes get pictures of my youngest daughter. The last time I got out of the Pen, I tried to locate her, like, see what I could do to get her back. I wanted to change my life and stuff, but she was already getting adopted. They were just waiting for her final HIV test, and then they were balancing on it. My youngest girl will be four years old this year. I pray for them every night, too, that they're loved as much as I love them, and they're cared for, and nobody touches them the wrong way. And I pray that I'll live old enough to see them, like, when they get older.

Every so often I get another letter. Just recently, I phoned the adoption agency, and I asked them for another letter, and they wrote me a letter about all of them, and they're all growing healthy. Developmentally, they're all where they're supposed to be at.

I remember going into labour. You know, every time I went into labour, I'd been just coming down from a drug high. It's bad, but it's true, right. I'd been just coming down, and waking up after the delivery, looking over, and there's either my older brother with my baby, or else my younger brother with my baby. My middle child, though, they tried to say I had TB, eh, and they took her right from the room. Nobody got to see her except for my younger brother, his ex-girlfriend, and my friend. I never got to see her because they said I had TB. They did all the tests. I stayed in for 3 or 4 days after that, I think, and they would not let me see her. I knew they had gotten the test results back and I wasn't positive. But they just did that, probably because of my history with my other daughter. At the end, my mom was the only one that was allowed to see her. My mom went every day, and since I couldn't see her, what did I do? I went back out and said, "They're not going to let me see her anyways," right, "so I might as well get high."

Sometime after the birth of my second daughter I found out I was HIV positive, that was like eight years ago. When I found out I was in a correctional institution. I remember when I got called to medical and I thought "well, what could this be about?" I still thought it was in Africa... and then when I got there, there was like five or six doctors and they said ... "Tammy will you please have a seat" and so I did and they told me "You have the virus of HIV" and then they sent me back to my cell block. When I got back to my cell all my friends come running: "What's wrong, baby? What's wrong, baby?" and I didn't say nothing, but they knew and they started crying and hugging me and I was like still wondering. I didn't feel any different and then I phoned my mom when she was alive and she was just crying. My mom had been going to dialysis for the last 10 years of her life, so she might have heard from there about HIV and that people would die and that from the nurses and staff, 'cause they used to know her well.

At the time I thought "Oh my god, I am going to die", but then nothing happened for a long time.

I told my dad. I told him in '98, and it was funny. 'Cause he had fell off the roof a long time ago— he was a roofer, and he got brain damage from that fall. I was drunk and I was crying, and I said, "Dad, I got HIV." And you know what he said? He held me — "Well, big girl, it's partly me and your mom's fault." [laughs] I just looked at him and I kind of started laughing. "Okay, Dad."

As for my brothers they were like "So what, you are still my little or big sister?" They both were hurting I could tell, but I couldn't say anything ....because I don't know, cause I thought that that was how they were dealing with it. But with my older brother, you could tell in his face he just wanted to hold me. But we were, like you know doing our thing. It's really hard, because I wish that if anybody had it, that it was only me, not me *and my brother. Because, what's going to happen to my younger brother when we're both gone?*

After a while I started to realize that living with HIV does not mean you have to give up on everything you love... you can either take it as a death sentence or you can use it to make you stronger and do the things that you really want to do. When I was first diagnosed with HIV I didn't know anything about it and over time I learned. When I think about it now I think everything happens for a reason and there is a reason I am still alive today even if I have the virus.

At first, other than my older brother my family knew nothing about it. They know my brother and I were sick, but they didn't know nothing about it. Even when I first found out, I didn't know anything. You know I thought it was in Africa. When I used to go to the rig exchange, I'd look at them AIDS pictures and I'd think, "Them poor people." When I first found out I thought, "Okay, I'm dying." That's all I thought. I was, like, wondering, "When am I going to die? What's going to happen?" But it was not until one winter *where I thought I was going to die and I really got scared for the first time. All the other times, before, I'd be, like, "I don't care if I die." But that one winter, I couldn't talk. I think I had the flu, or pneumonia or something. I didn't go to the hospital, and I think there must be reason I am still around and that's why I'm so thankful to be here and so healthy, because I [pause] I shouldn't be here. So now I know, I am going to be around for a long time.*

When I first got sick, I thought everybody would hate me, I thought nobody would be my friend and stuff like that, and for the longest time when I was out there, I'd cry if somebody yelled at me. Not any more. I am pretty honest with whoever I am with. If I feel like I can't trust them, I'll talk to them, like, as nothing — like I'm not sick or nothing, and then after one week or two, I'll tell them I'm HIV-positive. I'll look at, see what their reaction is, and if they don't like it, too bad. All my friends know that I am HIV positive. I didn't take them long to accept it ... because I was still me. I was never really sick *around them. Only years ago in the dope houses, that's where I'd be sick, but other than that, everybody treats me like me.*

When I was pregnant with my third daughter the doctor tried to put me on AZT. At the time, I thought, "When I get sick, it's not gonna help me," so I didn't take them. But I wasn't thinking. I didn't know it would help my baby. I was really lucky, because they were all clean anyway.

Most of the times you know when I think about this, living with this disease is like nothing. It's because I don't think about it, I don't — nobody talks about it. It's normal, so it's —. I don't think I'm going die soon. Like, I have a lot of faith, and the Creator kept me here for a reason, 'cause I should have been dead so many times. And I don't think the creator is just going to let me live for one or two more years.

without my mother or who am I?

My mom died in 1997, I was pregnant with my youngest daughter at the time. I got escorted from the prison to the hospital for two hours. Within that two hours, they made us wait in the waiting room. I got five minutes with her. She had tubes all over her. I remember the last words I said to her. I said, "Mom, you can't die. I'm not grown up yet."

Sometimes I think — like, she never drank after dialysis, right, and my auntie took her out. I went home to my auntie's for — I don't know why I went home, but I went home, and my mom was just drunk and happy. "My girl" — she had no teeth, eh? — "this guy asked me to dance and everything!" [laughs] She was so happy, eh? She was sick the next day though, because she was still on dialysis, but she was so happy. "My girl, this guy asked me to dance and everything!" and I think about that and I laugh.

She is in better place now, she is alright.
She is looking after my older brother
I know she is, but I mean,
I'm just so scared.

My brothers have always been important to me, but after my mom died they were all the family I had. Yeah. I miss my older brother, you know. Sometimes — I'm always calling my younger brother by the name of my older brother and the way we figure is that that person is thinking about us. I don't know why he doesn't call me. He remembers things from our growing up years that I don't. Like, I don't — well, I remember a couple of times, I used to steal hash from him. [laughs] But he remembers stuff like "One time we used to do this, Tammy, we used to do that," eh? I'll be looking at him, like, "Hey, right?" He'll be, "Yeah." I'll be, "Oh, okay." I miss him. I'm really worried about him, you know. Him and his girl-friend, they got a kid, and he was trying so hard to keep his shit together.

When my older brother found out he and his girl friend were HIV positive, he wouldn't tell me. For the longest time, they wouldn't tell me, eh. Because, I felt that they had it, since they were sick and stuff, right, and I'd asked them. But whenever I was in the

Pen, I'd say, "Honest to God, do you?" and they'd say, "No, no, no," but in my gut, I knew, eh. So when I got out — I got out August — March — April — [laughs] I got out sometime — and they were in treatment, and I went there, and he told me. He said, "Yeah, we got it" and I looked at him, and he said, "You think I'll tell you in there? You'll go crazy."

My little brother had to grow up mostly by himself 'cause we were all too fucked up, right — pardon my language. But when I told him, he just, "It's okay, Tammy." And he's a really big boy, if anybody said anything against me, like, this is his sister, you know. That's how he is. A while ago someone called and told me that my youngest brother was downtown and was getting beaten up. I was just about crying when I heard, because I've seen my older brother get the shit kicked out of him once and so that's all. I think, "Oh, my God! My little brother's going to get a licking," right, so I sent my brother down there. They came back, and my brother stayed the whole day, but they *stayed in the back, eh, because they were drinking. My youngest brother lives with us now and I feel secure when he is around me. My youngest brother and his girl-friend do drugs, but when they do it, they will get a room somewhere and will do it there, so I always still know where he is. Well sometimes, like, he doesn't do it in the house, but he goes outside and does it around over there. I have no problem with it, it's better than what he used to do.*

We haven't seen my older brother for sometime now and we just miss him. We went looking for him a few times. Sometimes I look at his picture and I cry, because in the wintertime, he's going to get sick, too. He is. I know he's going to get sick. I don't know if this time, he's going to make it, and it's scary. And we don't know nothing. Next time we'll probably hear from him is when he's in the hospital. " You know what? I'm really, really scared. I don't think my brother's going to make it that long. He isn't taking his pills, he's doing nothing. Last night my youngest brother and I were talking, and I said, *"I'm so worried about him and he said, "I know." I said, "And baby." I said, "I don't think [pause] he's going to make it that long." And my youngest brother said, "Yeah, I know." So I said, "We'd better stick together."*

Now I know my oldest brother is lost, but there's nothing I can do. I've been there, I've done it, and it all gets thrown back in my face.... Trying to hide the pain. It's not going to work. I tried that for how many years. So I have to change my thinking towards my family quite a bit because I can't take them. You know I want my brothers to grow up... I just miss him awfully.

Our conversations always returned to talking about family. For Tammy, family provided her with an identity, an identity that was otherwise shattered by marginalization, violence and a deep sadness of not knowing much about her cultural background. Family resembled an emotional and spiritual gathering, a bond made of feelings and belonging.

When I first got out from the pen, I felt like I have to do everything I could because my mom was gone and I am the only girl. That's how I felt. Even my youngest brother, sometimes you know he hugs me, and he's said, "I know we never had the times to grow up together, like, really," he said, "and I love you," and he said something like, "You're taking Mom's place." And I just about started crying, you know. Like, I told him, I said, "Wherever I am," I said, "you know you'll be there. If the guy I'm with won't take it, well, he's gone."

Remember my mother's blanket, you know it is a give-away blanket. I used to go to this native thing. It was like a course, kind of, to learn more, and we'd make stuff. Like, this drum and I have lots of native pictures, but I don't have them up any more. We always had the sweetgrass, but, I feel like I have been cheated out of my culture, because we never learned about it. Like, my mom spoke Cree — and my aunties — I remember, because we used to get sweared at in Cree. [laughs] But we were never taught it. We never went to — like, nowadays, look, there's Prince Charles, there's Ben Calfrobe school. I've never — you know. I wish, though I was given the opportunity when I was younger — I would have turned out better if I would have known more about my culture. I just learned about it in 1999.

It's weird, my whole time — like, I've been in institutions forever, right, and every time I heard there was going be a sweat at the prison, I always went halfway and then turned around. Like, I really wanted to do it, but I was too scared. There's probably a *reason for that, 'cause there were probably a lot of unclean people going, right. Then when I got to the Pen, the first time I heard the sweat, I asked, "What do I wear?" and I went, and I haven't quit since. This is what keeps me straight, my spirituality, my culture. For awhile after I was released I continued with my sweats and my smudging. But then I stopped, I got lazy, I quit smudging and then when I did fall and used drugs again, it was only for 2 days, and I could have got back up, but in my eyes, I had to punish myself, so I made the parole board send me back to the institution.*

Aboriginal culture is a strong thread interwoven in the lives of women of aboriginal heritage and influences their being and patterns of behaviour. Knowing about her aboriginal culture and the strong emphasis on connections with other human beings and spirits gave Tammy a strong sense of belonging to a larger community. This sense of community and the sense of living in a good way (Van Uchelen et al, 1997) helped Tammy to make sense of her identity. Most of all a deep sense of spirituality underlies Tammy's sense of being aboriginal. It is through this deep sense of spirituality that Tammy is also able to deal with her illness (Mussel-Oppenheim, 1993) and find a deeper purpose in life.

It's weird. It's difficult thinking of all the mistakes and stuff. But I have a lot of faith, too. We go sweat every weekend. I used to smudge every day until my brother moved in. Nothing bad or nothing. I just don't know if they're clean or not.

When you go to a sweat, it's — for me now, I go to pray for my family. Like, "Please take care of them" — and my boyfriend's family. We both have screwed-up families, eh. Well I mean, just like me: I'm straight now, and my brothers are screwed up. So we go to pray for our families. It's really — like, hmm, it's out of respect, and that's where we get our strength from. And smudging, too. After you smudge yourself, you feel like whatever you had has been lifted. You know like how people go to church and they sing and clap and that? That's how our sweat is. We go and we sing in the sweat lodge, and we pray real hard and it's just a wonderful feeling. If I didn't — when I first got out, I tried the church thing and stuff, but I still went to my sweats. But it's just not the same.

Coming out of a sweat after you're done, you feel so — like a rag doll. Like everything, like everything that you had in your mind is all left there.

Sometimes I go see an elder and sometimes my elder calls me at home, but I learned lots about my culture from my boyfriend. And there is also my friend. My friend is a Blackfoot Indian, and he's taught me lots about our culture and his culture and stuff. He also went to the sundance for me last year for my sickness. And then, I guess, he fell again. But he's always been there for me, and I just pray that he doesn't go to the next world. And he was just always — like I never thought that he'd be in hospital before me. I was crying last night when he left. Yeah, I just started crying. I called him and I said, "My friend is gone." I smudged yesterday, and I burnt a candle for him all day, and we're going smoke a pipe this weekend for him.

And when I lost him, I felt [pause] mad at him, like — when I, I was so mad, I wanted to just tell him, "Damn you!" you know. I was supposed to go first, not you. We both said, you know, "You'd better get better, or else." He said, "I will. Don't you worry." But now I guess he is looking down on us now. Looking down at us, saying, *"Don't worry, my angel. I'm up here!" He called me his angel. Yeah. I opened his heart up. Like, "You've done time? So what? So have I." He wrote me something once. "My angel, you'll always be my angel. I'll always be here for you. I love you in so many ways, and for so many reasons, because you know me and understand me like no one else ever could; because you believe in my dreams and care about my feelings; because you make me laugh so hard and smile so often, but mostly because you're my very best friend."*

My friend helped me too when I was so tired, tired of the staying up days after days, heartache, missing my family — everything. When I met him, he was a big tough guy who was in jail for 10 years. I started talking with him and then every night, we'd just talk and talk and talk, and I broke him out of his shell. Like, he was really quiet and silent. Like always had his back to the wall. Like, very institutionalized. And then we got out the same day, too, and we stayed close friends, my family knew him and sometimes he stayed over at my place.

I learnt a lot. I learnt a lot over the last little while. I guess I'm growing up. Like, for the longest time, I was a baby, and in the last 2 years, I guess I really [pause] learnt a lot. I told my cousin, I said, "Look, I've been on the streets, I've been hooking, I've done everything for over 10 years," I said, "and look I straightened out. Look what I got in return. I got a beautiful home, I got a beautiful boyfriend, I got beautiful step-children," I said, "and I was nothing." I said, "You're something. You got a beautiful child."

When I first got straight, I just loved it! I felt like I was walking on air. Then when I'd see my friends or something, I'd think, "Too bad." But then I was clean for, like, a year, but still — to me, I was done, I didn't need counseling, but of course, I didn't know about the cleaning trip. You stay clean for a while, then all of a sudden, you go back down just as quick as you got up. So when I cleaned up, then I went and got high, and I felt guiltier than guilty! Then after that, I went back to the pen and I thought all that guilt

I felt wasn't worth it. I said, "If I get high, it's going to be on my own head, not everybody else's, looking down on me," right? So now, it's my choice not to get high.

The counselor told me "The first thing you've got to do is cut off all your old strings." I thought, "Oh, God! I am not leaving my old friends." and I thought I would never leave my friends; they're my family. When I think about it now, actually that's not what I call a family, all of us asking each other for a hoot, and then once somebody leaves we're swearing at each other. It took me a long time to realize that we weren't a family, 'cause I grew up down there. Now I hardly talk to anybody on the street. But if I go to some place and I see somebody, I'll talk to them; I won't stick my nose up in the air.

reclaiming motherhood

I was on the phone with my ex-boyfriend, and I got mad and I shut my phone, and I said, "It's not going to work." I guess I was trying to find a relationship like the one I have now. At the time this guy I have known for a long time was sitting there, and he goes, "Well, if it doesn't work, I'll always be here," and I looked at him, and I said, "What?" He goes, "Yeah." I said, "What?!" and he goes, "Didn't your brother tell you I've always liked you?" "What?!" After that, I went home I couldn't believe what he had just said.

We ended up going together. It was really hard, too, when we started going together, because I'd always think of, like, "Does he know how I was?" So I asked him and he knows everything, you know. I'm really lucky. Yeah, he knows what I have done in the past and that I have straightened out now. Every day he tells me he's proud of me for being so strong, and I just tell him it's the kids and it's him.

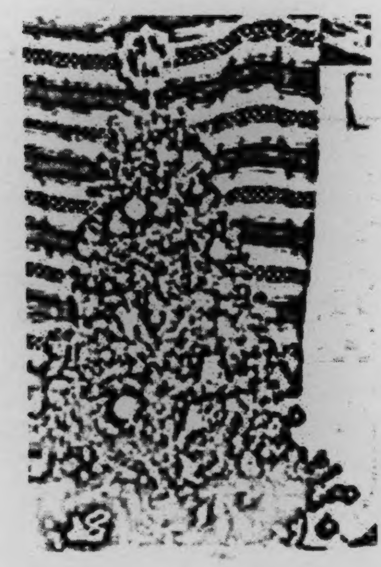
For my birthday, he bought me 25 roses, and a card that was this big. And my outfit and everything. I just [pause] I wish [pause] I pray some day [pause] I pray for the girls out there that they find what I have. But you know what? Most of them find it, and are gone for a couple of years, but then they always come back.

At first for the longest time I was debating whether to go with him or stay with my old boy-friend and try and work things out and I asked my auntie, "Who should I go with?" "Leave those jailbirds in jail alone!" she tells me. Then I asked my youngest brother , "Who should I go with?" and he goes, "Forget your old boy-friend." I think my brother's really proud of me and really respects me more because of the way I am now. Like, the way I keep the house, the way it's —.

So I left my old boy-friend behind and started this new relationship. The oldest daughter he has, she really did not know what to think of me when I got here. I think to her I was taking her daddy away and she would always say stuff like: "Where is my mom?" or "You are not my mom!" The youngest, always called me mom almost right from the start and then one day she said: "When are you and daddy getting married?" My jaw dropped and I said "I don't know, why do you ask?" She answered: "Well I want you and daddy to get married" and I said "Really?" and she said "Yes". I was just like "wow", it really meant a lot to me, because I thought that in their eyes I was going to be the wicked step-mother. Looking back, I think she just needed some reassurance that I wasn't going to just leave, when she just got used to me and plus she really wants a MOM. This was really what I needed to hear and so I told my man. Well eventually we did get engaged, and have been for the past 8 or 9 months and maybe by next year we will all be a real family.

Oh, I forgot to say that I am the one that is at home with my children all the time, so I guess that they should know if they want me or not. At times in the past I was wondering if they would really tell me the truth about how they feel about me but I don't worry anymore. I tell, the two girls often how much they mean to me and I just hope that someday we will all be a family. When our relationship first started I wanted to jump right into it, and then I had to remember he just got divorced, right, so I gave him time, and in the fall we talked about getting an engagement ring and he said, "That'll be your Christmas present."

Actually this was my first Christmas, since – well my last two were in the pen, and before that, Christmas day was "What? Is it Christmas? Oh, okay." I was thinking this year I want to get the house ready and everything for Christmas. I didn't want anyone else putting decoration up without me. I said, "I want to do it, because this is my first Christmas."



I feel really lucky. At one time both of my brothers and their girl-friends were living with us. My oldest brother said something like they feel they're taking over our place, but I said, "Don't feel that way." But [pause] you know, I want them to grow up and find their own space. Especially because he comes home — he works 12 hours a day — he comes home, he's tired, and he wants to spend time with us. He doesn't complain about my family living with us; he doesn't complain about nothing. He tells me that my family doesn't bother him when they're here, because they just watch TV and that. But he's used to having his own home, too. He doesn't even let his brothers come here, you know, and he's doing it for me, plus we're trying to help them out, right. But I just have to thank him so much for doing this for me, [pause] and I think I'm asking a lot of him.

Except he doesn't like it when my guy friends call and so I told him how I felt: "These are my friends. We have been through thick and thin together, and I'm not going to give them up. I love you, you're the one who I'm with. You're the one who I'm with *every night, and that's all that should matter." He said, "Okay, well, then we'll come to an agreement, that when you're on the phone with them, I'll walk away. Okay?" and I said, "Okay." I said, "But you got to understand, my friend's dying," right?*

Well, at first it was, like, exciting to be in this new relationship. Then it got, like, "This is all I do," and now, it's "This is what I have to do, and this is what I'm here to do, and this is what I'm alive to do." That's what I believe, because I should have been dead a long time ago. Like, probably —. And you know he stuck with me through thick and thin, and I put him through hell and back, and [pause] I love him so much

He's got a really good job and he takes good care of us. I still don't know how I got so lucky. He also buys a lot of vitamins for me and I take them every day, like vitamin E, ginkgo, actually, I quit taking the ginkgo because just in case. 'Cause it says on the bottle if you're pregnant, don't take it, right, so I told him I don't want to take it any more. And I got vitamin B, vitamin E, multivitamins, woman's vitamins. We spend lots on vitamins. We go shopping lots. And then well, we go to movies and stuff or I work out in my room during the day.

Vera: Did you set a wedding date yet?

Tammy: *No, no. I got to finish paying off my bills first, and then I can do that, because I have to get off welfare. I have to do that, right?*

Vera: So is that what you are dreaming of to be married?

Tammy: *Yes, I believe we'll be married, having a baby. 'Cause the way I went with my own kids, right, I just hope and pray that some day, I'll have a baby. I pray every night that I have a healthy baby, and a chance to look after it.*

The other day I was just doing my dishes and the kids were sitting here. They had their plates of food, and their birth mother comes walking into the house. Her oldest daughter didn't even look at her and I think she sensed that "She hasn't seen me for a long time." I kept on doing the dishes and my youngest brother was there talking with her and I looked back — behind my back, she and her sister were looking like they're better than me. I just thought, "Oh, well, I'm feeding her kids, I'm taking care of her kids."

Yesterday, we went shopping for the oldest one's school clothes. Oh, I think I had more of a ball than she did! [laughs]. She's going to be the coolest kid in school. The younger one, she's got lots of clothes that still fit her, eh, plus the older one's clothes that are still like new, she can fit those, so all we really have to get her is a jacket and runners. I got her a little pair of shoes, but that's just 'cause I felt bad 'cause we bought her all a bunch of stuff, eh. I bought her a suit. I don't know. I guess they've quite taken to me. I'm so glad.

I think this weekend we're going to try and go — oh, we can't even go to church or to our sweat, because we're having the oldest one's birthday party. I spent all my money on her. And they're going to their mom's for the weekend, which really bothers me lots, but I got to understand that they are hers. But if she don't want them —.

Sometimes I will say things like, "Oh, I got a headache," and the youngest one will say "Mommy, I don't want you to die!" She's really concerned about me and she worries when I get sick. It's really weird how close I've gotten to them. You know, the first day they came home — they came home a week after I got out from prison, and I started doing everything with them. [laughs] It was funny. There are times when I just watch them play together, and I can't believe it. Like, how close.

We have done lots together as a family, but the only thing we haven't done is, we haven't taken a family picture in our family yet ...

Being a mother was one of the most rewarding and exciting experiences for Tammy … not only did she have such an urgent need to show her mothering skills, she also had so much love to give.

Tammy's body was full of giving and receiving life and if I were to describe her words like warmth, touch, loving, vigorous and passion come to my mind. Tammy was filled with such possibilities and "these places of possibility within ourselves are dark because they are ancient and hidden; they have survived and grown strong through darkness. Within these deep places, each one of us holds an incredible reserve of creativity and power, of unexamined and unrecorded emotion and feeling. The woman's place of power within each of us is neither white nor surface; it is dark, it is ancient, and it is deep" (Lorde, 1984, pp. 36-37). Looking at Tammy reminded me that beauty and inner strength are present in our lives irrespective of our health status.

and then some more

A couple of weekends ago, I felt like — you know. I said, "I feel like I'm getting bored." And he said, "What do you want to do? We'll do it. We'll do anything you want." Drugs didn't come to my mind. It was, like, going to the bar, playing pool. Because I never really did that; I was always in a dope house. I said, "We can go into the bar and play pool and have pop, right?"

Sometimes I think about it, but not really. I think if I were on my own right now, I would not have everything I have, though. I would have nothing. I'd be some place, doing nothing, except for getting high. But then again, I think if I were still free — like, not free — like, "If I wasn't single, I could be doing this and that." Then again, I think, "Why do I want that? I have somebody that loves me, and we have a good relationship. Everything is good." So I don't even like to think of anything else? Like, at first, the first few months, I'd be thinking — 'cause when we started, I had just left my old boyfriend — I was *thinking, "What if I were with him still" — you know. I don't know. It was just too weird. I knew I wouldn't be having it as good as I have now, but it would be more —*

Well, you know, honestly — I screwed up last weekend. I took off and I got high. And I never got high for the longest time. I took off from home and I went to my friend's and I got him to score for me, right? I don't know how I got the money. Then all of a sudden I was just crying, eh, and crying. Doing my drugs, and I'd cry. My friend said, "Phone him before it gets harder." Like, phone right? 'Cause he knew I was doing good and that, right? Then I said, "No, I don't want to do it." Then finally, I phoned him, and I cried to him, and I said I was so sorry. "I'm so sorry," I said.

And the kids were wondering, too, if I was coming home. — "Where's my mom? Is she coming back to me?" I said, "I'm so sorry." And he asked me what I did. I said, "I got high." But it's — I think now it's going to be easier, because in the back of my mind, I was still thinking — not really that much, actually — not even — no, I don't think I was *ever thinking about getting high. Like, even the thrill of it, there's no more thrill there; there's nothing. I found out this time. Like, it was just — it doesn't even work to take the pain away any more. So I called him, and I apologized. I cried my eyeballs out, right. I kissed his arse [laughs] and then he goes, "So now what am I going to do? I got to start all over? I got to get a baby-sitter?" and this and that. I said, "Oh, so I'm your baby-sitter?" [laughs] So he said, "No." Then I can understand where he's coming from. So I said, "Can I come back or not?" He said, "Yeah, I'll come pick you up. Give me 20 minutes." So I waited. Then I phoned him back. I really wanted to leave, because people were coming back with dope, right? So I really wanted to leave, right? So I phoned him back, and he has a flat tire. I said, "Can I take a cab?" He said, "Yeah." Even when I phoned him, there were people inside still smoking, and they offered me, and I said, "No." So I took the cab home. I got home, and the kids, "Mommy, why are you crying?" "It's nothing," I said. "It's my fault," I said. "Mommy did something wrong." And I* *hugged him, and I apologized, and I told him this and that. In his mind, it was, like, "All this for dope." And I even got — who knows how I got the money, this and that, right? So he waited until Monday, and then he says, "We're going to go work out," right. So I'm, like, "Okay." 'Cause I got home Saturday morning, he waited till Monday, and he takes me to my friend's. He goes, "Wait in the truck." I'm, like — So I'm, like, sitting there, and I'm, like — you know. But he went in and he asked them what I bought. My friend's, like, a little old man, so he probably got scared and just told him, right? So I'm, like, "Oh, my poor friends." I was sitting in the truck, just thinking, "He could have told me. I would have came." I was just mad, eh? He goes, "A rock and a half!" You know, this and that, this and that. "How'd you get the money?" this and that. Next stop was the medicentre. I knew from there we were going there. Thought, "Okay. You want to go like this?" I said, "Okay," and I just sat there. We were just mad, eh? We went to the doctor's, I did my thing, and I knew I didn't do nothing wrong. I knew that. So he's at the* *doctor's, in the room with me, all this time, and I'm sitting there thinking, "It's going to be clean, and you're going to be the asshole." And I sat there, and I didn't say nothing to him. I said, "I understand." I said, "The way I used to be, that's how I used to get my drugs, right?" I said, "I understand." And I'm sitting there, and the doctor comes in, and sends him out. "You can't be in here when I'm" — I kind of started laughing, eh, because I knew that. So when I came out, I just went walking straight out the door, and he goes, "So now what?" I said, "They're going to call me on Wednesday." Just walking, 'cause I knew nothing, right. They called, and they laughed in his face. [pause] I said, "I don't remember," I said, "but I know." I said, "I know." And I understand where he's coming from, because when we were first getting together when I was still, when I'd take off, that's what I was doing, right, until I really got it in my mind that if we are together I can't do this. I understood that. I talked to him, and I said, "Why didn't you tell me? I* *would have went with you." He says, "You wouldn't have agreed." I said, "Yes, I would have." I said, "I told you how sorry I am." I felt, like, this small.*

We're good now, because the results came back. But I could tell he was always thinking of something, eh. So I was thinking, "If something is there, so now what? Like, what's going to happen?" I just ignored the thought, because I just thought — nothing is there. We were, really, like, in bed. We'd lay down. He'd lay down first, and I'd stay out. He took me home, and he went and worked out, and came back, and I was watching TV, just quiet. He comes and gives me vitamins and water, and I just looked at him, like, "What the hell are you doing? [laughs] Are you mad or what?" So I stayed up for a long time, eh. Then I went — after he went to bed, I went to sleep with him, and he didn't kiss me in the morning, and that really makes me mad when he doesn't kiss me before he leaves for work. So I asked him. I said, "Why didn't you kiss me this morning?" And he said, "'Cause you didn't kiss me good night." So I'm like —

The last while has been hard for Tammy. Once she returned to her substance use the drugs took over again and her life became chaotic and unpredictable and it was as if living on the street made Tammy forget everything. Eventually the relationship with her boyfriend ended. When I see Tammy now I noticed how even her dress hangs off her body loosely, as if her dress somehow remembers her body from before, before the drugs took a hold again …Tammy knew that the drugs made her do things she normally wouldn't and she said in one of our conversations *at least you have seen me when I was normal ...*

tribute to my family

Dearest family ~ this is what family means to me:

Family means unconditional love
Family means understanding
Family means sticking together
Family means being together
Family is the most important thing to me
Family is loving one another now and always
Family is helping each other
Family is listening to each other
Family means sharing each OTHER'S PAIN
Family means dealing with it together
Family means talking with each other

I hope you know how much you all mean to me, you are my world now and forever. I just want our family back the way it should be and it would be all good in our hood because our family is all we have.

Love, Tammy

My relationship with Tammy and her life story has had a profound effect on me and I miss her these days when the substance use prevents us from getting together like we used to for hours, going swimming with her children or to the mall or sitting over coffee wondering about our lives …

i just want my child to know that we care

Deanna and Joseph in relation with Vera Caine

August 2002

i just want my child to know that we care

acknowledgements

i remember

my sister

falling

betrayal

it is no longer just me, it's us now

a letter to remember me by

acknowledgements

This book is to show people the way we lived and survived. However, most of all it is to our children, to let them know that we never gave them up and that we never stopped thinking about them or loving them every day of our lives.

Love, Deanna and Joe

Dear Julien;

You must have been almost two years of age the very first time I met you and it was sometime before that when I met your mom and dad, Deanna and Joe. It was in the late fall of 2001 that I met your parents for the first time and I well remember the day … but it wasn't until days later that we sat down to record their life stories.

I am not sure Julien, where or who you will be when you get to read the words or see the pictures between the pages of this book, but there is something you should know and never forget, your mom and dad loved you and they cared about you so very much. your mom always said, *I just want to make sure he knows that we cared…*

I remember the first day I met you, your smile made the whole room glow and you made all of us forget where we came from and where we had to return to after our visit with you.

I sat down with your mom and dad many times and they always told me stories about their lives that made me think and wonder about the resiliency of the human spirit … about families and children … about life in a world where violence and passion are a steady companion … stories without end or beginning … and like their stories I hope this book is neither the end nor the beginning of you finding out who you are and where you came from.

with love, Vera.

i remember

As we slowly entered the parking lot her words continued to speed up, stopping only occasionally to breathe and laugh … this is how it always was just before Deanna got to hold Julien again. She was talkative, bubbling with joy and anticipation. More often than not we talked about her son, her older children, and life with Joe, though today we talked for the first time about her childhood memories.

I hate peanut butter sandwiches, because that's all we ever ate growing up, you know? Deanna didn't wait for my answer, instead begun to described vivid memories of living in poverty, parents that were rarely present and her grandmother who tried to help both her and her sister. Joe and I listened intently … *my sister and I spent most of our time alone, my mom would just leave us, often without any food. So when we got older, my sister and I would go down to the local store, fill up the shopping cart and make a run for the door without paying for it. It worked pretty good and we never did get caught.* Her eyes laugh as she remembers this part. *My grandmother too she would feed us sometimes ... you know, and then she called Child Welfare because she knew mom was never home*

... but then I even called them when things were really bad. I remember being hungry lots of times, looking for something to eat. Sometimes we would go to my grandma's and she would feed us, but most of the time we ate peanut butter and bread. You know, I still can't eat that stuff ... My family, when I was growing up — like, my family's native, right, but they think they're white. What they think is — they know they're native, but they pretend they're not. When I had native friends, it was bad. It was bad to be native, and they're native, but they thought they were white, so I don't know nothing about my background. My dad wasn't a lot around. My family didn't like him. He was always in jail, anyway, so I had nobody to even teach me that stuff. I didn't know nothing about a sweat until I — actually, not long ago. I went with my two other aunts who had to go up for a sweat. And I learned about elders and stuff like that, when I went to Poundmaker's last year.

Vera: Was that the first time you learned about your cultural background?

Deanna: *Yeah. Like an elder was there, too, eh. It was weird when I went there. They seem to know lots, eh?*

Joe: *Yeah.*

Deanna: *They knew lots.*

Joe: *Just know. It's like they were waiting for us.*

Deanna: *That's what he said. He said, "Been waiting for a long time for you to come here. It's about time. You'll be okay now."*

Living in poverty results in destruction over and over again … and stories of survival. Even as a child it was Deanna's responsibility to manage poverty, to find solutions and to negotiate with agencies, such as Social Services. Poverty often forces people to engage in illegal activities and many young people are forced to engage in sexual and drug-related activities to survive (Matiation, 1999b). Spending much of her time dealing with poverty as a child also left few resources for Deanna to establish her identity when she was younger (Malin, 2000).

Every now and then Deanna would provide me with a glimpse into her childhood, yet it was rarely more then a few words. Once she said there has been a lot of abuse in my history and at one other time *I have been abused in so many ways*. Whenever she did say these things they were surrounded by silence … no explanations, no attempt to make sense in words … sheer memory.

Twice she talked about the death of her mother. Her mom passed away when she was twenty-two … *to identify my mother's body after she died. That was hard, but I accepted it. At first, they were trying to tell me that I couldn't see my mom. I was, "Who the hell do you guys think you are? You cannot stop me from seeing my mom." When I stood up to them, boom, I went to the hospital morgue right then and there. But I was really mad at my brother, 'cause that's his choice. If he didn't want to see her, then that was fine, but he shouldn't have told them I didn't want to see her.*

'cause I always have these dreams, and still in my mind, even though I haven't seen her and I know she's gone, but it's really not in my head she's gone. I still think she's out there. When cars drive by and I'm out there, I look for her. I'm always looking for her. Even one time I was out there and I just started bawling. I thought I saw this girl — I saw this girl in this car, she looked exactly like my sister, and I just screamed her name without even knowing it. She was looking back, she kept looking back at me, and that just freaked me out even more. I'm, like, "She kept looking back at me, she kept looking back at me!" He just grabbed me and hugged me. I always think I see her. I have these dreams. Dreams that she's okay, she's happy, she's at peace now. I had a dream about her the other night when we slept for almost 24 hours. I had this dream about my sister, but it was really different. I can't really remember it. But she was trying to wear my pants, pants that I just claimed from this other girl. I asked her to borrow them, and I just claimed them, I didn't give them back. My sister was at my room at the hotel, and she says, "Deanna, let me wear these pants." I says, "No, I'll never get 'em back!" and I

turned around, and when I turned back, she was wearing my pants, and my sister said "They look good."

In my dreams, I always acknowledge, "But you're dead." I always say that to her and she always replies "But I'm okay." "Didn't you hear you're dead?" Sometimes she'll say, "No, I'm not. It wasn't me. It wasn't me" and she'll just, like, smile at me, like, "I'm okay." But that one time in my dream, I dreamt that there was an apartment building at the corner, and me and him lived there, and I was out working. I came back, and he's got this big smile on his face. He's, like, "Look who's here." There's a girl sitting there, and I could see the back of her head, and I thought it was one of his girlfriends or something, and I was just ready to start freaking. But she turns around real slow, and it's my sister. And she just smiled, and I just started crying. I said, "It wasn't you, it wasn't you! I knew it wasn't you." She just grabbed me. "No," she said, "I found myself on the news, and I was high, and I was all tweaked out, and I was scared, and I didn't know what to do, so I just stayed away. I didn't want anyone to see me. But I'm okay." It was just really weird. That dream just freaked me right out. That really, really freaked me out, how she just was faced, just her neck, just the back of her head, and she *just turned around really slowly and just looked at me and she said, "It wasn't me." What really freaked me out, though, is she said, "I was really high, I saw myself on the news, and I was all freaked out, so that's why I just stayed away." But the way she was talking and everything, she's, "I'm okay." I was just, "Whooa!" When I got up, I still had goose bumps and everything, eh. I always have dreams like those, eh.*

That's why I think, once I see those pictures of her after she was murdered — like, I know she's gone — in my head — but my heart doesn't want to believe it. And I know it's going to be more hurt for me, but I think it's going to be better for me if I see those pictures. I think she's trying to let me know she's okay, but at the same time, I'm getting mixed messages, you know? The thing that bothers me, too, is I think why I'm also having these dreams is that it wasn't her, that she's somewhere, she's still out there. Nobody actually went to see her body. My brothers, nobody would go to see it to make sure that it was her. The cops just told them. And you know what? The cops asked if somebody wanted to see. They didn't even ask me, they didn't even give me a choice, 'cause I would have went and seen. My brother just right away said, "No, nobody wants to see her."

(   )

Deanna: *When my sister passed away, I got more comfort from his aunt than I did from my whole family put together.*

Vera: Right.

Deanna: *'Cause I couldn't really deal with it. I didn't really accept it. When we got to his aunty's place, and I saw aunty, I gave our son to him, and I went right to aunty, and I told her. I said, "my sister is gone." And she just grabbed me, and she cried with me. And she never treated me any different.*

Joe: *My family would never treat her any different.*

Deanna: *We buried my sister on his birthday. Seemed like I had no way to get to and from the funeral. None of my family come and picked me up. They wouldn't come pick us up, they wouldn't do nothing for us. And they knew that I'd be taking it the hardest. But still, "Oh, the funeral's not till 10:00. You guys can get up and take the bus down here."*

Deanna: *She's the only one I had besides him and baby. I don't care what anybody says. I don't. When it comes to my sister, it's just —. When the cops left yesterday, they had picked us up yesterday, they had pictures of my sister, a whole bunch of mug shots, and one of me in the corner when my hair was short. 'Cause I got jumped by about seven girls, and my hair was long as it is now, and they cut it off with a butcher knife, so my hair was about this short on top all the way around. It was just growing back. And they had that mug shot of me. I said, "Lookit! That's when I got my hair cut off!" [laughs] I said, "Is that pictures?" He says, "Yeah." I said, "Of my sister?" He says, "Yeah." I said, "May I see them?" They looked at each other and he's, like, "I don't see why not." First thing I thought was maybe they were pictures of when they found her. That's what I thought it would be. But it was just mug shots of her over the years. But eventually, I want to see those pictures, because I know they have pictures. I know I'm entitled to that. I can see them. I know they don't want to show me them, but I think as a closure for me.*

Vera: Did they have a closed casket at the funeral?

Deanna: *Yeah. So I really didn't even have, like, really, closure, you know, and I think if I see those pictures, I know it might be even harder on me to see her that way, but I think it'll give me — I think I'll be able to kind of let her go a little bit more. I think I'll be more at peace. I know I'll be more comfortable. It'll be hard to see her that way, I know that. I can't even imagine what the pictures are.*

going to look like. But I think I'll be able to let her go, I'll be more comfortable, and I won't have that always looking for her. I'll know she's gone, even though it's going to be hard. I think I need to talk to that detective to let him know that. 'Cause right now, I think what he's worried about is me and my situation, how I'm going to handle it. But I think for me, to be more at peace and to let her rest, I have to see those. I do.

Vera: That is going to be really difficult.

Deanna: *I was down as the next of kin. I think they should have come and asked me if I wanted to see my sister. They said they come to look for me to let me know about her death, that I was one of the first people, but I honestly don't believe them. I honestly don't. They knew where I was living. They said they went —*

Vera: They knew where you work.

Deanna: *At the time, I wasn't working the streets. I was straight, too. I was doing really good, but when I found out about my sister, I didn't fall off the wagon, I took a flying leap off the thing, you know.*

Joe: *Didn't fall off; you jumped. Maybe that's why. They knew you'd probably fall again.*

Deanna: *But still, that doesn't matter because I was going to find out anyways. So now I want to see those pictures, but I'm going to wait till I know I'm somewhere where — I know J would be a support for me, but I want to be straight. I want to be able to properly deal with it so that I deal with it all, let it all out, I'm not* *carrying it around and stuff. I want him to be there with me. But I think that's something I want to do, though, really, really bad. I do want to do that. And I know once I talk to this detective, he can't say no. He can't say no to me. And I'm going to tell him that I wasn't given the opportunity. I could raise a lot of stink about that. After my sister, I just knew where I was headed, and I knew what I had to lose. At the same time, I had no one to turn to. I tried to reach out to my family so badly. I even went over there. I just went, and left him and J at home. Just wanted to try and get back in there, just to feel that comfort, to feel — 'cause I felt so empty, eh? Just to feel that sense of belonging. But they just turned me away. It just seemed like — I was trying to go to them, and for every three steps forward I'd go to them, they'd push me five steps back. Didn't matter what I said or what I did.*

For Deanna the death of her sister was one of the most difficult moments in her life; life suddenly didn't make any sense more and any meaning she could derive from it before was suddenly shattered. On the anniversary of her sister's death Deanna, Joe, Deanna's dad and I went to visit her sister's resting place. We took along some sweetgrass and food as an offering to the spirits. We did not talk much that day … it was only after our visit that I could feel the salt from my tears on my face mixed with the smell of sweetgrass and I longed to go home to place my arms around my sister's body, to soak in her smell and warmth.

names not yet marked in stone
but inscribed forever into the stories of our lives

What does it mean to remember?

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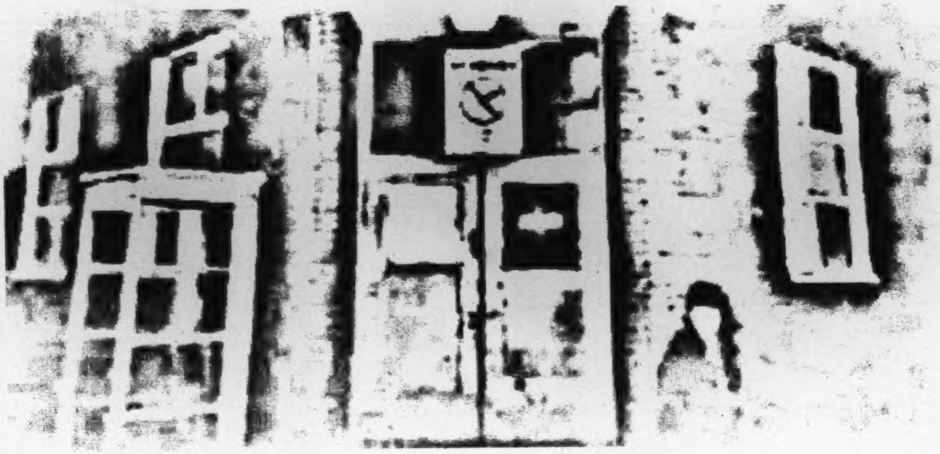
many would see Deanna and Joe as victims,

yet they also tell a different story,

one in which they tell new stories and un-tell existing stories



betrayal

betrayal 1

you should maybe try and educate yourself on it a bit
'cause people do have feelings
sometimes there's lots of things in the past which you guys have done
nobody throws it in your face
everyone forgets it

it won't happen again.
it happened once, and i should have known better.
i should have known better.

family won't even talk, won't even acknowledge me
the black sheep of the family
none of my family ever trusted me
it was hard

they're too good, or they think they are

when he said: "you AIDS victim"
he just made me feel like shit ... it was just another pile of shit

one of my relatives, she wouldn't even come in the house, not even the yard
she stood outside the fence like that, calling me
wouldn't even come to the door to ring the door or nothing

my family lied to me.
they lied
i want to tell them: "don't lie to me, because that hurts even more"

i tried to reach out to my family so badly
i even went over there
they just turned me away
i could feel the distance

my family
i couldn't see them for, like 5 years
and they wouldn't even notice it

Deanna: *At my sister's funeral, everybody knew that I was HIV-positive, and I didn't even tell my family that I was positive in the beginning. My aunt worked for a driving place with Child Welfare, a driving agency, and she told me that it was on file.*

Vera: She looked at the file, or —

Deanna: *Yeah, she was the receptionist, so she booked the drives and stuff, and when she found out that our son was in care, she just wanted to see how he was doing, instead of contacting me. She looked in the file, and in the file it said that I was HIV-positive. Me, and his dad, and we were positive, but our son was negative. So she must have told everybody. At my sister's funeral, nobody even really came by me. It was sad. It was hard.*

betrayal 2

my grandma, she acts like she is scared of me
when she hugs me,
it's not a grandma hug, it's like a get it over with hug

my grandma, she acts like she's alright and everything like that,
but she won't hug me
she used to always hug me and kiss me
she wouldn't even give me a grandma hug no more
it's like she's scared of me, but won't let me know
she tries to avoid me now when I phone her
she tries to be off the phone really fast
she tries to make it look like it doesn't bother her
but you can see it in her face that it does, just me being around her
since they found out that i am sick

my grandma, she acts like she is scared of me
when she hugs me,
it's not a grandma hug, it's like a get it over with hug

The betrayal Deanna experienced also was evident in how her family treated her son:

betrayal 3

everybody knew i was HIV positive
everyone just assumed that he had it, too

nobody would play with my son
they wouldn't let him play
they don't want their kids to play with him

i am not going to let anyone hurt my kids
he doesn't deserve to be hurt like that from anyone,
i don't care who it is

nobody picked him up
all he wants is a little attention
all he wants is to play
he is not hurting anyone

he wasn't old enough to feel the hurt
but he did sometimes and that was hard

The betrayal Deanna, Joe and Julien experienced didn't just occur on special occasions, it permeated almost every one of their encounters or non-encounters. Although recently, Deanna's dad has been trying to help Deanna and Joe as much as possible, their relationship in the past has been strained and Deanna often tried to avoid him. Despite knowing that Deanna would make money by engaging in sexual activities, her dad would often ask her for money.

Vera: He uses drugs, and drinks?
Deanna: *He does whatever he can, basically. He hasn't got any money. He just goes and hangs out down there. I told them last time, I said, "If my dad shows up here, tell him we are not here."*
Vera: So does your dad hang out a lot there?
Deanna: *Just recently. Right now, he's trying to get money of me, and he's trying to stick around.*
Vera: Does he know what you're doing?
Deanna: *Yeah. I told him that.*

There were many more incidents of continued betrayal, but it always came down to:

Someone making promises or lying to her
hurt Deanna more
than
living in poverty,
being raped or going hungry
or being HIV positive

Deanna sometimes talked about her HIV positive diagnosis; mostly it was about the responses she received from other people. However, even her positive diagnosis can be seen as a betrayal "an emotional rape, a violation of a person's innocence, of their guarantee of a future and their right to health" (Weiser, 1996, p. 21). Deanna was often concerned about herself and Joe's health and she worried whether her declining health could be restored. On her good days, days she didn't have any physical ailments her anxiety dissipated only to always return much too soon.

Deanna would seek medical care only when there was a severe crisis. Once we ended up going to the physician together and all they did was take blood, they didn't even ask about her psychological, social, or spiritual well-being … never mind spending attention on her liver and kidneys … On another occasion Deanna went for a pre-admission for a day procedure at the local hospital:

> *The doctor checked everybody else, but a different doctor was supposed to come in for me. Probably because I'm HIV positive is why. I was waiting for him and waiting for him. We were just watching TV. I'm sitting there, and I had my feet up, my shoes off. Then at the last minute, she says, "The doctor said he's not — you can get dressed. The doctor's not coming. Just be here at 8 o'clock. We're going to give you something before you go in for the surgery".*
>
> *On a prior occasion ... they did the same thing. I was on morphine every 4 hours, whether I asked for it or not. I was constantly high. The day they discharged me, they gave me another shot and kicked me out. Nothing to come off the morphine or anything. I went home, I was so dope sick for — I was morphine sick for about a month.*

Ignoring women's health and illness concerns, another form of oppression, is frequent in health related research. Lack of research leads to inadequate medical knowledge of women's health issues. As well, inattention to women's reports of health and illness minimizes their health concerns and complaints (Gillespie, 1995; McBride, 1993). This lack of knowledge about the impact and effects of HIV on women's lives often results in inappropriate and detrimental care being provided (Gillespie, 1995).

The women in Nicholas and Schilder's study (1997) felt that health care professionals were uninformed of the manifestations and impact of HIV/AIDS on women's health and moreover felt discriminated against in the health care system based upon their disease and gender. Semple et al. (1993) identified multiple psychobiological stressors among HIV positive women. Health related stressors included general symptoms of HIV infection and gynecological problems. The psychosocial stressors these women experienced were related to their family, marital/partner relations, occupation, economic problems and social network events, such as the death of friends from AIDS.

In a study conducted by Stevens (1996), women living with HIV/AIDS perceived health care contacts and cooperation with prescribed regimens as opportunities for HIV to take over their lives; they therefore avoided contact with health care providers.

For Deanna the contact with health care providers also left her with a feeling of guilt and shame fostered by their perception that HIV is "yet another chronic disease affecting those that fail to follow an appropriate lifestyle of safer sex and clean injection use" (Jackson, 1997, p. 38).

Deanna's encounters with the social services system and in particular the Child Welfare System was part of many of our conversations. *And trust is a really hard thing for me when it comes to child welfare, because — I have four children, but I lost my oldest three just after my mom passed away, and it was kind of the same thing. I signed the custody agreement, but the worker that I was working with wasn't working with me, she was working against me, and I did everything. I thought I was doing really good and I went for everything they wanted me to do, to see the psychiatrist and everything. In the end, my depression was used against me, and that's how I lost my children. I was doing fine. I quit doing drugs, I was giving clean drug testing, I went into treatment, I went for parenting assessments — everything. I even had my own place. In the end, it was my depression that made me lose my kids, from my mother's death. The psychiatrist went in there and said that — she went to court, and she said, "When we go to court, don't worry. We're going to get your kids back." I went in there thinking I was going to win and I was just happy. I believed that I was walking out with my kids. That psychiatrist went up there, said it would take a minimum of 5 years for me to even start to deal with my depression, and they cannot keep children in care for 5 years, so they were granting* *permanent guardianship. So right now, when I signed this custody agreement, I bawled my eyes out. My child welfare worker — my aunt was there when I signed it. I made sure I had somebody on my side. I made sure she wasn't the only worker sitting there, telling me, giving me false hopes, basically. 'Cause when I signed the custody agreement, they could have apprehended — but my worker was really good. We have a good relationship, the three of us — four of us — and she could have apprehended, because we had a positive drug screening. But she gave us the choice to sign the agreement, and then we have more of a say, and it'll be easier to get our son back. But she also had the apprehension on it in case we didn't sign it. So I signed it. I'm really glad that I'm working with her, and that's why we want to move into that area. So then we're still in the same district. If we move to a different district, our file will be transferred and we'll come to a new worker. We might not be as lucky and have someone to work with us. I could get the same child welfare worker as I had last time, and I'm not willing to take that step. That's why, if I have to keep signing these custody agreements until I get into her district, that's what I'm going to do, 'cause I know she wants the three of us to be together. She doesn't want to break us up. She cares about us. Like our medication and* *stuff, medication-wise. She knows that I'm not on them, and , "Did J get his meds?" [laughs] She kind of gives us shit, but not to make us feel uncomfortable. She's a good worker.*

S.

she is the only one really standing beside us and has any faith in us

she cares about our son
she goes out of her way to check
to make sure he is okay
to make sure he's happy
to make sure he is taken care of

trust is a really big thing for me

she is trying to watch out for our son
she is trying to watch out for us
she is doing the best she can basically for all three of us
she doesn't want to break us up
she cares about us

she is the only one really standing beside us and has any faith in us

I told her that, too
I have never lied to her
I have always been honest
I never said I wasn't using
I think that's where we got the respect from.

trust is a really big thing for me

Much to Deanna's and Joe's dismay the positive relationship with their child welfare worker was very short lived. Without warning, Deanna and Joe were asked to appear in court, as Child Welfare was applying for permanent guardianship of their son. Just days prior to this the child welfare worker had discussed with them a substance use treatment for both Deanna and Joe and a plan that would allow their son to spend more time with them and eventually return to them. They never did see their original child welfare worker again and in retrospect are thinking that they have trusted her much too soon and too much. It is not surprising that Deanna and Joe, like many other parents, have a fair amount of trepidation when they approach the social services system, particularly since it is difficult to identify whether or not individual workers will be a source of stress or support (Marcenko & Samost, 1999).

Deanna and Joe were told often what they had to do to get their child back, but never was any form of assistance or support offered. Only once did the child welfare worker go out of her way to assist Deanna and Joe with the application for a treatment centre. However the process was never completed by the child welfare worker despite being reassured that she had done so. At other times they were told that without a telephone they could not be notified when their next visit with their son would take place.

Deanna and Joe were never offered counseling to deal with the apprehension of their child. Yet it has been recommended that "social workers should be prepared to offer counseling directed at repairing the disrupted relationships between mothers and children or resolving guilt and other feelings associated with children who are no longer part of the family" (van Loon, 2000, p. 160).

Their son was asked to undergo several development screening tests to detect if he was affected by the substances Deanna allegedly used during her pregnancy. Although test results are needed to ensure access to resources for the child, they were also used to make Deanna feel responsible for her behaviours and for any developmental delays her son would experience. After all, in their eyes she was irresponsible.

We had a parent aide — actually two of them, but I was doing their job for them. They weren't doing nothing. I said, "I don't want to work with them. They are not doing anything. Why should I work with them?" She was cancelling appointments, and saying that — trying to make it look like we were cancelling. So I phoned my worker and, she said that she's cancelling, and she'd cover our butts. Why does she have to cover our butts, if she's the one canceling the appointment? It makes it look like she's not working with us. So we got her, her supervisor, our child welfare worker, and the supervisor of child welfare — like, the six of us in there. And I had everything written down. I said, "I don't want to work with her. She's not doing anything for us." I'm doing her job. She's supposed to be writing all these notes and stuff. She's asking me to write them, and then she'll photocopy and give her a copy of it. I said, "No, I don't think so, 'cause then I'm doing your job for you. If you give me half your cheque, I'll do it."

Sometimes, even with the visits, like, I was really mad 'cause I went to meet my son in an old child welfare building. I went with my sister-in-law when they didn't show up. I waited there for an hour and 40 minutes. My visit was only 2 hours; they didn't show up. The driver had said that he had brought my son there. There was only one *entrance. I didn't see them. He said he left at 20 to 5:00pm. I waited outside from 4 o'clock until 20 to 6:00pm. So I don't know what happened. My sister-in-law was there with me. I told my worker. I said, "I was there." I was in the day program at AADAC at the time. I graduated that day, and I went to go and have my visit with my son, and he did not show up. And I was phoning. I was trying to talk to backup workers. It really pissed me off, 'cause the backup worker didn't know who had my son, who the driver was, how to contact him, and they couldn't locate the foster parents. So at the time where I'm trying to visit my son, they didn't even know where he was themselves.*

When applying for welfare the social worker Deanna applied with made sure she knew how powerful social workers could be.

When I went in there on Thursday afternoon, I explained my whole situation to her. I just sat down and I said, "Listen [...]" I told her, "What's happening is I'm going in for surgery. She said, "Listen, you got all your paperwork done." And I was supposed to go for an intake before with her. I told her, "I know I missed that other appointment. I'm not going to miss this one. It's really important." She then says, "Listen, if you are here tomorrow at 8:30, I'll guarantee you'll get your cheque tomorrow afternoon." She says, "It's amazing what I can do for people." She says, "This one girl comes in" — she goes, "But you seem to be pretty honest and everything, and you seem to be in a bad situation. I like to help out people like that. This one girl walked in here with such an attitude. She argued with me about everything." She says, "And I can work wonders for her, too. She didn't get her cheque for 2 weeks."

At other times child welfare workers ensured that both Deanna and Joe knew that once something was written on either of their files, true or not, it became permanent and unerasable.

Joe: *Welfare thinks I beat my ex-girlfriend. She's doing that just 'cause she's —she was smoking dope, but she blamed it on me, that I took it out on her, started beating her and stuff, and then she'd go into those safe houses, 'cause they'd pay the rent and the damage deposit'.*
Deanna: *She just needed a place to stay and some money..*
Joe: *And I didn't even know. I didn't even know about it, that I was beating her.*
Deanna: *Until I was pregnant.*
Vera: *And then it all came out.*
Joe: *Yeah, a big file on me like that.*
Deanna: *'Cause I went to social services, and of course, when you're pregnant, they ask you who the father is. I told them. I had to go in to pick up my cheque, and my worker called me in and she told me. She said, "Do you know that the father of your child is a very abusive man?" I said, "Oh? Really? Where you getting this from?" I said, "I've been with him" — and at the time, it was probably 4 years, eh? Had to have been; our son is almost 2. Four years. I said, "I been with him for 4 years, and he hasn't hurt me." Says, "Well, there's a big file with" — they said his ex-girlfriend claimed that she'd been — that I'd better be careful, because there was a big file. I said, "I knew all about that," I said. "When I first started going with him," I said, "she was in one of those safe houses," or something, because she was doing drugs, and that was her escape. They had a big file on him, anyways.*
Vera: *And that was the first you'd heard about it?*
Joe: *Yeah.*

Because of her substance use, Deanna's and Joe's role as parents fell outside of expected socio-cultural norms and lead to stigmatization and discrimination. Yet, they were also stigmatized because of their positive HIV status. Unlike other diseases, HIV/AIDS elicits feelings of personal responsibility and blame (McDonnell, 1993). Lawless, Kippax and Crawford (1996) in their study "Dirty, diseased and undeserving: The positioning of HIV positive women" examined the stigma experienced by women. Like Moneyham et al. (1996 b), they found that the stigma of sexual deviance and promiscuity is often attached to HIV/AIDS. They discovered that part of the stigmatization women experience is "based on the assumption that women have departed from the socially prescribed behaviour worthy of good women" (p. 1376).

Researchers have yet to examine the complex interrelationship between race, class, and gender as it interacts with women's knowledge of their infection and the effect this has on the burden of oppression and stigmatization (Bunting, 1997). As a society, we too have to spend time thinking about and naming the tensions and struggles added to peoples lives when they are stigmatized or discriminated against. People, like Deanna and Joe are often made (and made to feel) responsible for the rise in infectious disease, crime, substance use, and gang violence. In essence, they come to "embody the necessity for welfare reform, as if they sit at the heart at the moral decay" (Fine, Weis, Weseen, & Wong, 2000, p. 109).

"but every place she went
they pushed her to the other side
and that other side
and that other side pushed her to the other side
of the other side
kept in shadows of other "
(Gloria Anzaldua, as cited in Minh-ha, 1991, p. 14).

it is no longer just me, it's us now

The statistics behind people affected with HIV or AIDS are daunting, yet they do not show how people come to terms with their illness, how it affects their everyday lives, nor their encounters of racism, discrimination, or injustices. After her sister's death Deanna was left without her strongest personal social support system. Deanna and Joe were left to deal with their HIV positive diagnosis on their own.

Deanna: *Yeah. It was just me and my sister. It was always just me and my sister. Then my sister passed away, and now, it's just me — me and him and my baby.*

For Deanna being HIV positive meant having to cope with numerous physical ailments. As with other women, Deanna struggled with physical symptoms such as a reduction in energy, difficulties with daily activities and frequent pain (Sarna, Servellen, Padilla & Brecht, 1999). Stevens (1996) explored the perception, evaluations and responses of women related to their HIV symptoms. The women that experienced an accumulation of overwhelming symptoms grew very fearful of these symptoms and attempted to protect themselves from allowing HIV to control their life.

Deanna: *No. Last time I was there — last time I was in to see my doctor, she even wanted to put me on meds. She went on holidays, and the doctor that was taking her place wouldn't give me nothing.*
Vera: Because you didn't want to make the decision and — oh, not even the pain killer?
Deanna: *Not even my pain killers, no.*
Joe: *She tried to say that she's —*
Deanna: *She tried to say she'd already gave them to me. But I argued with my doctor. I said — I went right in there, and I was freaking right out. I said, "You can ask the nurse here." I said, "I didn't get no — I didn't get my medication, I didn't get my pain killers. Not even my pain killers, never mind starting me on meds." She wouldn't start me on nothing. She wouldn't give me nothing. When I go in there, I was just, like — I was sick, I could barely even move, and she acted like I was faking.*

Vera: So did you end up having to buy pain killers off the street?

Deanna: *Yeah. [pause] Well, he did. [laughs] Lately, we have mostly been sleeping, so we haven't actually been doing much. Just sleeping. We're behind two days on our rent.*

Vera: What a vicious circle.

Deanna: *And with us sleeping so much, it's just — we can't stay awake. We'll get up and we'll eat or something, and then right back to sleep. I didn't make my appointment Tuesday. I couldn't get out of bed.*

Vera: Yes. Are you going to try and go next week, just to get that checked out?

Deanna: *I'm just sick. I'm just not feeling well at all. I'm going through really bad sweats, really bad night sweats.*

Joe: *She won't go to an appointment .*

Deanna: *Even underneath my armpits hurt*

Joe: *I know, I been telling her, but she doesn't want to go. Too stubborn.*

Deanna's physical ailments were aggravated by the continuous struggle to locate housing. At the time I met Deanna and Joe they were staying at a hotel in the inner city. Recalling our first meeting, I had never been to the hotel before and even before I entered the door was greeted by signs stating: "No knifes allowed on the premises" and the smell of stale beer, urine and feces. I remember my (dis)ease as I stepped through the doors. As Deanna and Joe led me up to their room the smell from bathrooms intensified, to the point where I almost gagged. I noticed the doors of many of the rooms we walked past were open; old men with bottles of liquor in their hands sitting on their beds and gazing at us, only made my discomfort grow. I breathed a sigh of relief when we finally arrived at their room, a room filled with piles of personal belongings stacked in corners. On my first visit I hardly looked around feeling much like an intruder on their most private space. It took several visits before I could smell the coffee and food that was being prepared behind closed and open doors, and recognize the loneliness of the men sitting behind open doors, and the home Deanna and Joe were living in.

Joe: *Yeah. You should see it sometimes.*

Deanna: *It's just nasty. When we first started staying there, I was using the sink in our room, I was too scared to go down the hallway to use the bathroom. [laughter] He thought I was going to break the sink, eh, 'cause I just climbed right up there, and I'm just sitting there. I was so scared. I wouldn't even go in the hallway, eh. And when we'd leave, just [laughter] all day, watching. I thought somebody was going to come and try and kill me, 'cause all these stories that I heard, and I was so scared there.*

Joe: *It used to be like that, now it's not too bad.*

Deanna: *Now I don't think nothing. I don't know why I was ever that scared in the first place.*

Joe: *Well, before, it was bad like that.*

Deanna: *Nobody ever tries to break into our room.*

Joe: *Everyone knows us, that's why.*

Deanna: *But sometimes when he's gone and I'm there by myself, they listen to see if I'm there by myself. Like, a few times, they try and turn the handle, and somebody tried to stick their own key in there and see if they could open the door. They know I'm alone, eh. They're trying to scare me so maybe I'll open the door and check who's out there, but I never open the door when he's not home. Never. Even when he tries to trick me. When he tries to trick me, I open it purposely, 'cause I know the way he walks. The click of the door when you pull that door,* I

> *just know when it's him, eh. I know his exact walk coming up those stairs, and his cough, and then he comes around the corner. He sticks his key in and he coughs again. He was trying to act like it wasn't him yesterday, eh. He was trying to get in the lock. It was him, 'cause I could tell — he didn't cough, but I could tell the way he walks, eh. So I opened it: "Honey, I thought I told you not to open the door." I knew it was you! [laughter]. And I don't know – last night, some reason, I was just so scared. I was just laying there watching the door. I don't know why I was that scared.*

Throughout their stay at the hotel Deanna and Joe struggled to meet their daily payments for the rent of their room. They continuously had to negotiate with the owner, as well as others working at the front desk.

Deanna: *And we didn't know it was in the bank. And then we took it out and we paid for the room. That was 3 days ago, because we were 3 days behind then. We just paid it all off. We used it on the room, eh, and now we're 3 days behind again. But it's a different woman working. Like, the owner, she — during the week, and I'm sick, she always sends me to bed. She's not worried about the rent, because she knows she'll get it. But the weekend staff, they double-lock the doors [both voices]. We have a key for the bottom lock, but not the top, eh. So they lock the top lock so we can't get in.*

Vera: And you have to, because tomorrow is Sunday. You have another couple of nights to stay.

Deanna: *They'll take the double lock off if we give them a day's worth, and then after tomorrow, it won't be anything, 'cause the owner will be back on Monday. [pause]But anything's better than paying them. Forty bucks a day, I'm sick of it. I'm sick to the point where they're sending me out to work. It's, like, isn't that against the law? [pause] One time, we owed $200. We didn't pay them up for a whole week. Paid it off in an hour. Sometimes it takes a little bit longer when I'm not feeling well. Lately, that's been a lot. But they always, always got their money.*

Joe: *We always have trouble with this one woman there.*

Deanna: *Yeah. She's really rude like that. I made a complaint about her, too, because my aunt — the day we went to the hospital — so it was Thursday, and I didn't want to go anywhere. We had no money and I didn't want to go to work, I just wasn't up to it. I phoned my aunt, and she says, "Okay, I'll bring you guys some groceries." She said she had some jackets and stuff for us, too, eh. She said she'd be there by 9:00, and if she couldn't make it, she'd call. We were just starving. We had two loaves of bread, and we borrowed a block of cheese from the guy next door, 'cause he always feeds us. If I'm hungry, I could go knock on his door. I'll wake up, my hair's all over the place, I've got my pyjamas on, "R, I'm hungry." "Okay, baby." Gives me something to eat, feeds me all the time,* *eh. When I'm not feeling well, he'll bring me, like, Nitol or whatever, something to try and make me better, eh. He always gives us steaks and stuff, and then when we got money, we just give him a couple of bucks. Went over there, I said, "R, I'm hungry." He gives us a package of ham and a big block of cheese. He says, "You owe me $5." I said, "Okay," and we went back and just ate that, waiting for my Aunty. We kept falling asleep and waking up. She didn't come. Here, she'd left a message and asked the woman at the front desk to come up and let us know she couldn't make it, to stop by her work Friday morning, and she would give me some money, 'cause there was no way she could make it down there. We never got that message. Here, I was sitting there, I'm thinking —*

Vera: "Where is she?"

Deanna: *I said, "Geez, I wonder why she didn't come." When we went to her work yesterday, I said, "I was waiting for you last night. I was just starving. We were eating bread and butter." And then we had to go and borrow some cheese and stuff off our neighbour. She said, "I phoned. I asked this woman to go up, and she said she hadn't seen you guys all day." She didn't see us. She told my Aunty she'd come up and let us know, and she didn't [pause] let us know nothing. She said, "I told you if I couldn't make it, I would phone you and let you know," 'cause I said, "I'm hungry. I don't want to go out there." I talked to the owner, too, about that, about me not getting my messages. I talked to her about that at* *lunchtime. When we got back from seeing my aunt, I told her about that. When I got back just before 4:00 before Joe got up and the woman was at the front desk, I said, "Is the owner here? I want to pay her." She says, "She's around here somewhere. Why?" I said, "Because she trusted me all week not paying my rent, she filled me out a rent confirmation, and I'm now going to be paying by the month." "Oh, is that so?" she says. She didn't believe me. I says, "Yeah, I owe her $425."*

So the owner come out and she looks at me. I says, "I'd like to pay my rent. You said I could pay by the month, and you're starting from my last payment date, so I'm due from the 28th, am I right?" She says, "Yeah." She looks at this other woman, eh. Who's, like, "I guess she could pay me." And I go, "Yeah." And she says, "Well, what are you waiting for? Do the paperwork." And the owner comes running out, she just grabs me and she hugged me and she said, "I love you. I knew you wouldn't let me down! See, all you got to do is have a little bit of faith and trust in people." And she goes, "Not everybody's going to let you down." When she's saying this, she's looking at the other woman, eh. It made me feel so good inside, I was just like [pause]

Throughout their stay at the hotel, they tried to find an apartment or a room they could rent. Deanna was particularly concerned with living in the catchment area of their child welfare worker:

Deanna: *Like, down here, we can get a place, and I think that's what we're going to do. See, with our worker, I told her that we'll get a place in his name, 'cause I'm the one that's signing the custody agreements. So that way, the file stays with her, right. So we're not there, and we can still have our visits at what they think is his place. But this way, she gets to keep our file, and once we get our life back on track, they've got nothing to hold against us, and then it doesn't matter if the file gets transferred.*

Joe: *There might be this one place, this guy renting out a house needs a handyman. Deanna called him.*

Deanna: *I just told him that I want it, like, right away. I told him I'm living in a hotel, I'm paying by the day in the hotel, and it's not even a nice hotel. I didn't want to tell him where. I didn't want to scare him off. I said, "I'm staying in a hotel right now, and I just need to get some place stable. Also I have a little boy that I'd like to bring home, but I can't bring him to a hotel room." He said, "Oh, I understand." He's really nice, though. Wednesday is when I'd be able to get everything done. I wouldn't have the money till Friday. But if he'd be willing to let him start to do the work on it, and giving him, like, $50 a day or something*

until next week, and then whatever it comes up to till then, and then Friday, just pay the rest of it, right?

Deanna and Joe finally found an apartment to live in after looking for over five months. Many times people would ask for references. *We don't have any references, 'cause we've always lived with family. They won't use family as a reference, 'cause of course, family is going — you know, [laughs] try and butter it up. And even if they're not buttering up, that's what it's out to look like*. Deanna also was very cautions of disclosing to people where they were living at the time they were looking for accommodations, because it usually was used to make multiple assumptions about them. In Deanna and Joe's eyes many people refused to rent to them because they were aboriginal. This was based on the fact when they initially called landlords they often received positive responses, but when they came to see the place in person they were told it was rented and once they were told people would not rent to aboriginal people:

Deanna: *So we're trying to find a place. It's really hard, 'cause there's lots of racist people out there. Lots.*

Vera: Yeah, it's difficult.

Deanna: *If it's not one excuse, it's another. They just judge us by our appearance or whatever.*

Although Deanna and Joe both received social assistance at times their substance use habit was forcing Deanna to work in the sex trade several times a week. Deanna has worked in the sex trade periodically over the past eleven years. She rarely talked about her work. Once she told me *last night I was raped by four guys*. It was in the middle of a different conversation, it seemed like an odd remark and I was puzzled by the way she continued with our original conversation. The indifference with which she reported the abuse to me still continues to make me wonder. I wonder about the physical, psychological, emotional and spiritual scars.

Encounters with the police were not unusual for Deanna. However one time, on a rare occasion, police officers seemed to show a genuine concern for her well-being:

Deanna: *What really freaked me out, though, is a couple of weeks ago, it was on a Sunday, I was standing there by myself, and there was no traffic. All of a sudden, the paddy-wagon pulls right up to me, with another cop car right after. They said, "We just got an anonymous call in that someone fitting your description perfectly was going to get hurt on this corner."*

Joe: *And they knew right away.*

Deanna: *They knew exactly that it was me. How many cop cars showed up there, just to make sure I was okay? 'Cause they all know me, I've been down there so long. I've been on and off the streets for the last 11 years, so they all know me. They pull up to me, they don't even ask me for my name. I just started going through the routine, they just laugh at me, eh.*

The only time she talked for a longer period about her work was right after the Christmas holidays:

Deanna: *We got lots of stuff for ourselves. You wouldn't believe the stuff I got from people off the streets. Yeah, I thought, "Oh, God, obviously, everybody's looking at me like I'm just a pitiful case or something, eh. But actually, I don't know. Like, three times, and I made over $400. So I was pretty proud of myself.*

Vera: Oh, really!

Deanna: *Standing on the corner, this man and this woman stopped. She says, "I see you out here all the time." She gave me two Christmas bags, one for me and one for Joe. She said, "I see you guys out here. One's for you and one's for your boyfriend." She says, "Merry Christmas." I just grabbed her and hugged her. I said, "Thank you so much. That means a lot to me, that you see me out here all the time, and you left to come here, like, take time away your family." Just to give me something. Another one — oh, that was somebody in a Caravan. Next, a little blue car with an older white couple, they come. They had this shoebox wrapped up. They had — what did they have in there? A couple of boxes of chocolates, shampoo, toothpaste, mittens — shampoo, t-shirt, mittens, chocolates, soaps, toothpaste, toothbrush, candles — everything. And a really nice card. I was just, like, "I can't believe it." This other woman invited us over to her house for dinner.*

Vera: That's great!

Deanna: *I didn't go. But still, the thought was there. If I needed a ride, she was going to come to pick us both up, drive us home, and make us turkey dinner. I saw her Christmas day. She was walking around. She has a vehicle, but she was walking around with a thermos full of hot chocolate. She asked me if I had mittens. She had a little gift bag about this big. There was an angel inside of it. What else did I get? Some soap, another angel, chocolates, and a candle, and a card.*

Working in the sex trade and finding a place to live was already challenging for Deanna and Joe, but at the same time they also tried to address their substance use. Deanna was well aware that their continued substance use was preventing them from seeing their son or having their son returned to them. Making matters much more complicated, she knew that her health was deteriorating much more quickly:

Vera: [pause] I guess this time you have to make the change for your son, don't you?
Deanna: *I have to make it for myself first, though. If it's just for my son —*
Joe: *It's not going to work.*
Deanna: *— it's not going to work. And I know I want it for myself. 'Cause if I want it for myself, then I can take care of myself, and then I can take care of him better. If I'm just doing it for him, what's going to happen when Child Welfare is out of my life? I'm going to go back 'cause I think I'm safe, and it's all going to happen again. No, I have to do it for me. And I want to. It's just really hard where we're at right now.*
Joe: *We have to go get treatment. We're going to go to — we'll get our rent sent there, but we go to treatment. First we got to go to drug screening; like, a few weeks for that – Maybe two weeks of that. We go through a program, and then the social worker is going to send us all of that.*
Deanna: *And then — as long as the drug screens are clean. If we got negative screenings for, like, a month straight, she'll send us all into treatment together so that we*

don't have to go without our son. I prefer for all of us to go together. I am willing to do whatever I have to do to get him back. I just want him back.

Vera: Does the treatment centre you are thinking of have an aboriginal component?

Joe: *Oh, yeah.*

Deanna: *I want my son to do that kind of stuff, but I can't handle it. Like, sweats? 'Cause I have asthma and I'm claustrophobic, eh. I can go in for, like, the first round, right, but mostly, I can't go past that, 'cause I almost faint going through the first one, eh.[pause] The last time I went to Poundmaker's I just go up to them, and he'd hug them, and I just said, "Don't hug me." But when we went into Poundmaker's, every morning, when we go into the — what's that — ceremonial room?*

Joe: *Yeah.*

Deanna: *The ceremonial room, and you do your prayer, and you smudge for the day, and you go around, and you hug everybody wishing them a good day and it goes until you finished the circle. At the first one, he's laughing at me. He says, "Just teepee hugs." 'Cause I'd just go like this and try and stay away. He says, "Quit teepee-hugging. Nobody here is going to bite you." He could see that, eh. By the time I left, boy, I was just hugging everyone! [laughter] You couldn't stop me from hugging you! [laughs] I liked it there when I went.*

Despite the challenges Deanna and Joe faced everyday, they strongly believed in themselves. They were always optimistic and hopeful that perhaps one day their life would be different:

Vera: And when did you fall in love?

Deanna: *I fell in love right away. He didn't fall in love till 4 years later.*

Vera: [laughs] You had a lot of patience to wait that long.

Deanna: *You wouldn't believe some of the stuff I had patience with.*

Vera: [laughs]

Deanna: *But I love him. I must.*

Vera: [laughs] Yeah, you must. [laughs]

Deanna: *I'm really ________________, first by telling him I love him. I'd say, "I love you." "I know you do." "Let's hear you say it." "I know you do." Or if he didn't say "I know you do, he would say "Me too." He didn't say "I love you." First time he said it, it just shocked me. "Yeah, I know you do." I just used to hate that.*

At the same time there were also moments when the challenges became overwhelming:

Deanna: *We been getting along actually a lot better lately.*

Vera: Oh, is that right? That's good.

Deanna: *Before, remember, I was telling you I was stressed out with the holidays and stuff. All the stress, knowing that we weren't having our son. Also, it was getting to me that we were still at the hotel and we didn't have our son. We've got everything. Now that it's over with, we did fine, the two of us. We did fine. We had a good Christmas.*

At other times Deanna and Joe had enough resources to care for other peoples:

Deanna: *We gave him sandwiches. But I mean, slowly walking home, do you know how many people we seen just going home that was just starving, that were just asking us just for a bun? And I stopped, and how many sandwiches I made on the way home? Do you know how many people I stopped, just on the way, just to give them a sandwich?*

Joe: *Only had a couple left for us. [laughs]*

Deanna: *Yeah, and we only had—*

Vera: You spent $20. You must have given out a lot.

Deanna: *I can't believe it, how many people actually out there really are hungry and stuff. And how far that $20 brought us. How many people we put a smile on their face and were so happy, eh.*

Joe: *Now everybody knows us! [laughs]*

Most often however Deanna and Joe talked about their isolation from others and their deep felt sense of loneliness. Living in poverty, with addictions and an HIV positive diagnosis seemed to have robbed them of their trust in others, consumed all their energy, and made them fearful of others:

on your own

no one comes and bothers us
we keep to ourselves
we are safer that way
with all the gossip, somebody could get hurt

that's why it's just us
it's just me and him
that's all we have is just each other

that's all i ever had, is him

they're not friends – when they got money they are gone

i don't have any friends
i don't talk to no one
i stick to myself
i am safer that way

Joe: *No one comes and bothers us.*

Deanna: *We keep to ourselves. I think it's just better that way. People are, like, "Do you know many people?" "No, we stick to ourselves. We're safer that way." "Oh, that's what I would say. I'm safer that way." Nobody can start "he said, she said" or "they're doing this, they're doing that."*

Vera: Probably happens a lot downtown, huh?

Deanna: *Just with all the gossip, somebody could get hurt. That's why it's just us, eh. And everyone knows that, so they leave us alone.*

Joe: *When we first moved into the hotel, oh, God, you'd just hear these guys who'd drink next to us, just talking about us, eh. 'cause we had no radio, nothing to drown it out, eh. I just opened the door. "If you guys got anything to talk about, come and talk to me to my face; my door's open." The whole place just went quiet. [laughter] "Yeah, that's what I thought." I slammed my door. "You got something to say about me, say it to my face. If something's bothering you, I'm here; the door's open."*

Vera: Do you have any close friends, even if they don't live downtown?

Deanna: *I don't have any friends. It's just me and him. That's all we have is just each other, right now.*

Joe: *Everyone that I know —*

Deanna: *That's all I've ever had, is him.*

Joe: *— they just want to come around when I got money or something. They're not friends. [laughs] When they got money, they're gone.*

Vera: Deanna, when you work at night, do you talk about that stuff with the others that work down there?

Deanna: *Nobody —*

Joe: *She doesn't talk to no one.*

Vera: You don't talk to anybody?

Deanna: *Not to anybody. I stick to myself. I'm safer that way. Because I find, even I stick to myself, I still get a lot of people trying to start trouble with me. So I can imagine if I talked to anybody. I just keep to myself. That's it.*

communities as places of

solidarity and compassion

imprisonment and isolation

Above all, Deanna and Joe valued parenthood. Their eyes laughed when they talked about their son. As small and young as he was he helped them make sense of their lives.

our son

when he sees us, he is so happy
it's hard saying bye to him
i always cry

it was so heartbreaking

he will sing in the back seat
when he saw his dad he just cried

that just broke my heart

i didn't really bother me that i had HIV
but then i didn't want my baby to have it
i just want to see my son

it was so heartbreaking

i just want him to know that we cared
i just want him to know that we loved him

that just broke my heart

i was really looking forward to seeing him
he is still such a good boy

We haven't met the family, but we have a contact book, so they write to us and we write them notes and stuff. The first family I don't think was very nice to him, 'cause they get money for clothing and stuff, and he was always dressed in rags. It was all hand-me-downs. He had gotten a cheque for new clothes, and that money is supposed to go to him. So I think the family was really in it for the money, because he had old shoes on. He didn't look like my baby, he just — I don't know. He looked like he was in hand-me-downs. Some of the pants he was wearing were too short for him, and babies aren't supposed to be dressed like that. The first time that our child welfare worker thought something was wrong, she moved him. She told me, not so much 'cause [laughs] she was scared that we'd get mad. But she said that he wasn't being properly taken care of in that home. I told her, I said, "I knew it." I knew it, because just the way he was dressed, the way he acted. But now he seems to be doing good. Even when they'd send a bag — send his diaper bag and have treats inside, it was always the same treats. Before, it was always the same treats. If he didn't eat them, they just stayed in there. Like, they weren't packing something new. Now when he comes, he's got all kinds of treats, and he's forever eating, and I can tell he's happy. So that makes it a little bit easier, because I know he's being taken care of, and I know that they're loving him as their own. They're treating my baby good.

Once we get into a place, our worker will probably come and check it and make sure that there's not a bunch of people staying there and that it's safe, and then we'll have supervised visits. And I don't mind if it's supervised; I just want to see my son. Well, *I don't want to bring him to the hotel. I haven't asked for that, but I don't want to. I don't even want to attempt to ask for it.*

I have to sign that agreement. If I don't sign it on Monday, she's got to go to court. They've got to have something with my consent, or else they have to have an apprehension. I won't let them get an apprehension. I'd rather do it this way. 'Cause right now, I have a say in what goes on. I'm more — it'll be easier for us to get him back home, as long as there's a custody agreement. See, when they apprehend, they can only keep a child in the system so long, and then they've got to go PG — public guardianship. With a custody agreement, it's an agreement; they can't just, "Okay, we're going for permanent guardianship." 'Cause they can't. 'Cause that custody agreement — if I had my own place, and if they just all of a sudden asked for a drug screening, and it came back negative, and we had food in the fridge and everything, if all of a sudden, I decided to cancel that custody, they have to, on those terms, because I'm meeting all of those terms.

When I was pregnant with him I was scared. I was so scared. Being HIV positive was the only thing I was worried about. It didn't really bother me that I had it, but then I wanted my baby not to have it. I was lucky that he didn't. Really lucky. Somebody up there is watching.

Deanna: *He's big, eh? He's not even 19 months old yet.*

Vera: He is big. He's got really good energy.

Deanna: *He's always been like that.*

Vera: He's a really good kid. And he's playful, and he loves to explore stuff. I laughed — with the camera, he was always after it.

Deanna: *The flash, eh. He liked the flash.*

Vera: He did. That was really good. No, he has really good energy to be around. It was good. I was amazed, too. When I was there, even after two and a half hours, he wasn't cranky, he wasn't grumpy. It was good.

Deanna: *He's a lazy boy. He didn't get up until 9 o'clock that morning. I couldn't believe how much he's grown.*

Vera: But it was good they dressed him really warm. It was too warm for the playroom, but it was still good to see that.

Deanna: *I'm happy with the family that he's with. I can say that I'm really happy with that family. Seems like they give him all the attention he needs. Doesn't seem like he's wanting or needing anything. And he's still such a good boy.*

Vera: Yeah, he's a really good boy.

Deanna: *And you can tell he's not spoilt too badly, and he's got a lot of attention paid to him, which is good.*

Deanna was often worried about her physical health, and voiced her fear of Joe or herself dying. Whenever, we talked about death it was in connection with dreams, real or imagined ones:

Deanna: *Every time I have one of those dreams, somebody dies. I told him that, too. I said, "It's got to be first Saturday morning that I —." Whenever I get these dreams — I get these dreams that you can't wake up. My mom showed me how. She said tell myself to ask so I know I'm dreaming. When I calm down, then I'll wake up. It's so scary. If I keep being scared, I'm not going to wake up. So I know how to get myself out of it sometimes. Every time I have one of those dreams, somebody dies.*

Vera: Do you actually dream in your dream that somebody is dying, or is it just a certain type of dream?

Deanna: *It's the same dream, and whenever I have that dream, somebody dies. I told him, too. I says, "Somebody's going to die. Somebody I know, somebody I love." Same with my sister.*

Vera: Oh, that's scary.

Deanna: *Same with my mom. When my mom passed away. Um-huh. I told my mom. My mom knew about my dreams, too, eh. I told her, too. I said, "Mom, I had another one of those dreams," and my cousin had that same dream. We had the exact same dream.*

Deanna: *I woke up and I phoned her. She lived in the next building from me. I said, "Did you have one?" She says, "Yeah." We took a cab, we went to my mom's, and I told my mom, eh. I said, "Mom, what if it's me?" "Don't say that." I said, "What if it's me?" My mom said, "Don't say that." "I don't __________________." And my mom looks at me and she says, "What if it's me?" I said, "I'd go nuts, Mom. Don't even say that." And it was her.*

Vera: But you never know who it is? You just know that it's somebody.

Deanna: *Somebody close to me. I always tell him in advance if I have a dream. If I have a dream, somebody's going to die, and it always happens, eh.*

Vera: So you actually know in advance that you'll dream it?

Deanna: *No.*

Vera: Just after it happened.

Deanna: *After it happens, I tell him. "Had another one of those dreams." [pause] When I was in Poundmaker's last year and he was really sick with TB and the HIV meds, and I was having those dreams, I went home for the weekend and cried. I was thinking, "Please go to the hospital." He went, and he just thought he was sick. I didn't want him to die.*

Joe: *What we're going to take mostly is probably the baby.*

Deanna: *Probably with baby. I think that's what our majority of it is going to go, is on our son. 'Cause I know all the cute things he does, and I haven't seen him for so long now. We have lots of pictures. Not with us, but you've seen some of the pictures. Since he's been born, we have so many pictures. I mean, I don't think I even that that many pictures of the rest of my kids, with just one pile of his pictures. 'Cause I know that we're sick, I want to have lots of this stuff. 'Cause I don't know when we're going to be gone. I just want him to know about, like, that we cared. I just want him to know that we loved him, and that we did think of stuff. Like, even these tapes, I want to save them for him.*

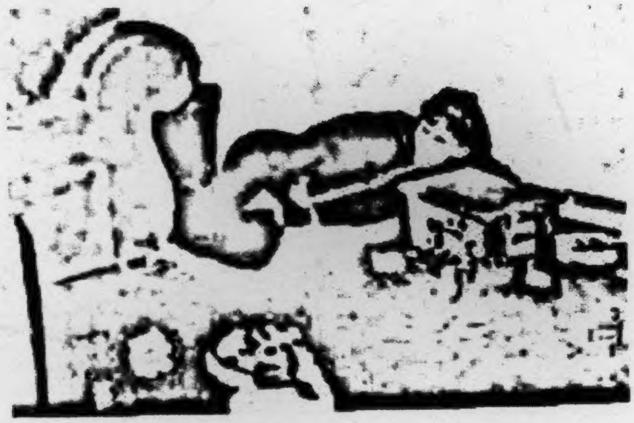
Vera: Yeah, they'll be good.

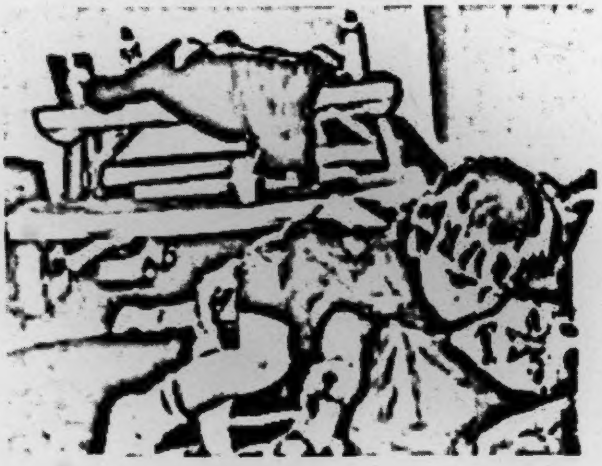
Deanna: *I don't know. I have all my stuff from when I was in treatment, and all the work that I did on my health, and all the feelings and stuff that I brought out, and all the mean things that I did, and how much of a mean person, but then I can be a good person, too, eh. My differences, just through all my work to be there, my son will know all that stuff. I want to keep all of that for him. When I did it, I didn't think about that, though? Like, I wasn't thinking about that, but now.*

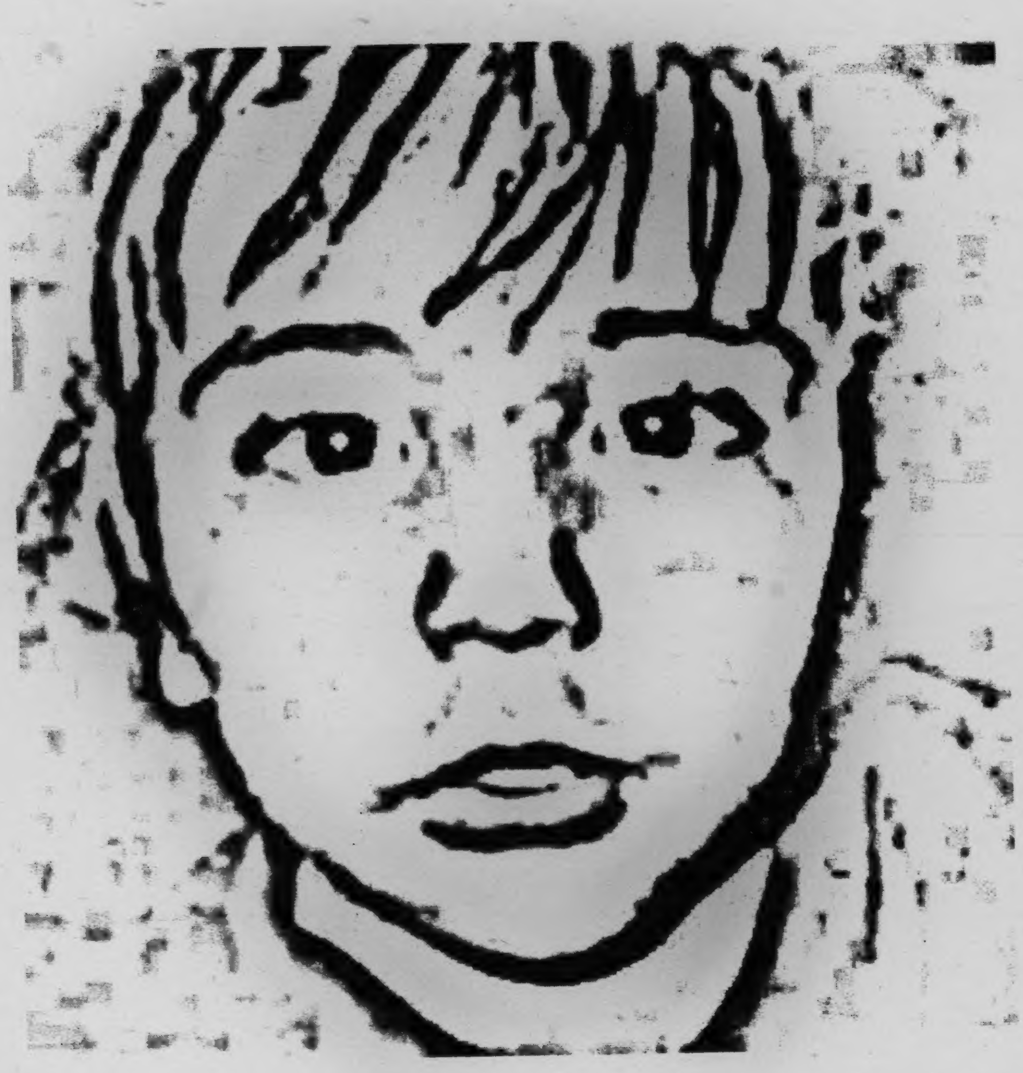
Vera: But now, you're starting to think about that more.

Joe: *I was almost dead.*

Deanna: *How close to death he came last year about this time. Just the way that — just how we've been lately, that's not us. We're usually up and gone or whatever.*







One day maybe our children will understand

that our lives were difficult at times and we didn't always do things the right way

because I don't know when we're going to be gone

I just want them to know about, like, that we cared

a letter to remember me by

and I still have half a heart left

Debra in relation with Vera Caine

August 2002

and I still have half a heart left

acknowledgment

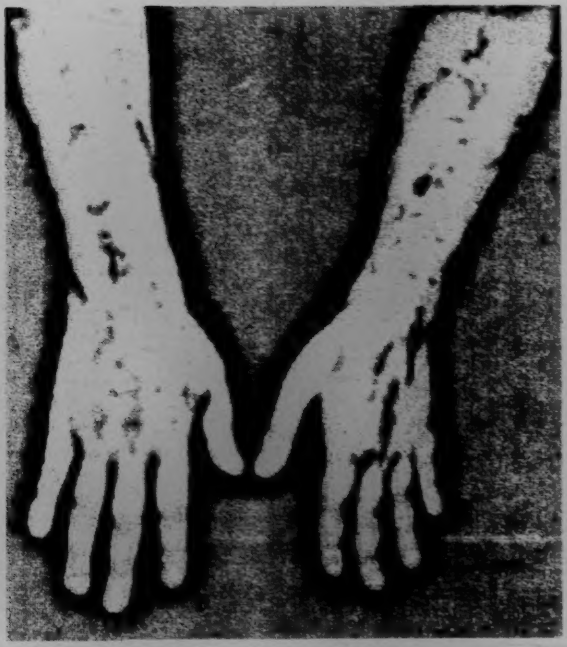
a postcard to a friend
scars of experience
to my mom and dad
to you my sister
a postcard from my past
to my sons
surviving
some other postcard
a postcard from a friend

acknowledgment

For my boys;

I want you to know how much love I have for you and I want you to know the truth.

Love mom.



a postcard to a friend

My dearest Debra;

I just wanted to send you this note
to let you know how honoured I feel
to have been part of your life, to talk
with you over coffee,to laugh with you
and to worry with you …

The last few weeks have been hard for
you … but I am amazed by all you have
accomplished. I know you too are proud
of it …

Alles liebe, Vera

For Debra

Vera: [very long pause] Do you have a lot of trouble with your arms?

Debra: *Oh, yeah. That's part of the reason that I'm on the morphine; it's for pain.*

Vera: Is it mostly pain in your arms?

Debra: *Oh, yeah.*

Vera: Did you ever use your legs or other parts of your body to inject?

Debra: *No, not so badly. Just my ankles. [very long pause]*

Debra and I spend much time talking and in silence wondering about her life story. I remember the first time we met, the middle of winter: cold and snowy. We were both so nervous at our first meetings, unsure what to expect … now we sometimes look back and talk about the uncertainty and hesitation that surrounded our first few encounters. Debra often speaks of the inability to trust someone immediately, the difficulty of knowing if the relationship will be helpful or damaging to her, or deplete her of physical and emotional energies she would rather use elsewhere. For me it was the uncertainty of knowing how to respond to her story and trying so hard to know what to ask, being mindful to not exhaust her personal resources to cope with her story told to a stranger. It took a few encounters for both of us to begin to trust our own abilities and intuitions, to know when to not ask or respond or when to be silent.

When we talked about taking photographs Debra's initial response was to take pictures of her arms. She slowly lifted her sleeves to show me the marks placed all along, side by side, the whole length of both of her forearms, and I remember the immediacy of the revolting feeling in my stomach, enough to make my eyes water and my throat close, afraid of throwing up. Ever since then the picture of her arms during all our conversations and thinking about her life became a physical, emotional, psychological and spiritual metaphor for the scars Debra's life experiences had left behind.

Vera: Have you always taken drugs intravenously for all those 15 years?

Debra: *Yes. That was scary. I thought I'd never do it, but I ended up [pause] doing it. Living on the street makes you do things that you normally wouldn't do.*

Vera: At what age did you start living on the streets, Debra?

Debra: *Thirteen.*

Vera: Thirteen. That's tough.

Debra: *For me to live a normal life is tough. Sometimes I find it hard to be normal, and I just want to go back to the street 'cause it's [pause] I don't know how to say [pause] more comfortable for me? And making change is harder. For anybody, I guess, for you to change to do something else, it'd be harder — and it's hard.*

what is normal?

is there comfort in normality and dis~comfort in oddity, strangeness, abnormality?

moving between abnormality and normality

or is it normality and abnormality?

or is it?

is the movement between abnormality and normality fluid?

is there movement?

what do normal people talk about?

Debra: *'Cause when I'm in with a normal crowd, I feel really uncomfortable. I don't know what to talk about or — what school did I go to and —. You know, I only went to the Grade 6, and then people look at you, and "How do you live if you never had a job?" Things like that that normal people talk about — their work or their schooling or whatever. 'Cause I've scared a few people away, probably, talking about my life, what my days have been like.*

Vera: Do you have friends that broke away from prostitution and drug use?

Debra: *I don't see them, or they have passed on because of a drug overdose, or a man has got them. There are quite a few girls that get killed, but no one hears about them, because they have no families. They have nobody to care about them. Sometimes I have a couple of drinks, just to build up my guard or whatever. And I'm very, very careful of who I pick and choose. If I get a bad feeling — because when that happened to me, I did have a bad feeling in my stomach.*

Debra: *Imagine the fear when it's the way of life. I had that happen to me, and the guy dumped me in a dumpster. I held my breath. I held my breath, and I ran out into the alley and I got hit by a truck. So there was a lot of evidence that was lost, so he got off. Because I was a working girl and used drugs, that was the reason for — I think a big reason for the judge's decision to say that I [pause] I asked for it, in other words — which I didn't.*

defining Debra by what she did and not by who she was
seemed uncomplicated and less demanding for many people
it also seems easier for people to fault individuals like Debra for becoming
HIV positive, rather than placing their risk of becoming infected within the
context of poverty, racism, sexism, discrimination and larger social ills
(Trussler & Marchand, 1997; Farmer, 1996).

Vera: So when you were 13 then, you just took off from the foster home?
Debra: *Just did what I wanted to do.*
Vera: Did you start living on the street when you were 13 years old ?
Debra: *I thought it was a good life. It was good money. I used to wear nice clothes, I always had money, everything was just the greatest. When I first started, we had fun joking around and making fun of the men that picked us up. Those times, I miss. There was about five of us.*
Vera: Is that when you started prostitution?
Debra: *Yes. That's how I got — I used to sleep in the emergency hospital, like waiting room 'cause I couldn't find a place to sleep, and there was where — 'cause every guy that allowed you a place to sleep, they'd want to touch you all the time, and I didn't like that. So I would sleep in the waiting rooms[very long pause]. How's your tea?*
Vera: I just can't imagine what that would mean. I can't.
Debra: *A lot of people can't, also.*

Vera: Have you struggled a lot with your body image?
Debra: *Yeah. For the work that I've done and stuff, I need to look good. Even if I'm not working, I need to look [pause] look better. I was always tiny, and I looked good. Took care of myself. I made lots of money.*
Vera: You had to grow up pretty fast.
Debra: *Yeah.*
Vera: Did you find that when you were younger there was a lot of older women who tried to teach you some of the street rules?
Debra: *They'd scare us away. Try and scare us away. We wouldn't —. Now I know why they did that. When I was younger, I didn't know why. I wish I would have listened to them [laughs]*
Vera: It's difficult to make young children listen, somehow, isn't it?
Debra: *Yeah, especially when they have their own rules.*

Debra did not talk a lot about her childhood; she remained very closed about it. I often wondered how much her childhood experiences must have disrupted her sense of self and identity. Moving from foster home to foster home, without ever really belonging. The first positive memories of her growing up years seemed to have been when she was beginning to live on the streets and had fun with the other girls, as if for the first time knowing she was part of larger community of human beings, or family. Whenever Debra describes those first few years of living on the street her body appears more relaxed and her eyes lighten up, remembering the good times amidst all that happened along the way. She never speaks about fear, desperation and loneliness when she talks about those first few years, it seems to become part of her story much later and appeared not to have been part of these fun times. But I wonder if not telling means they really weren't part of the experience at the time, or if Debra was unaware or inattentive to the feelings of fear and desperation at that time, or if not telling is an attempt to maintain an integral sense of self?

Debra: *And then I lived in Calgary for 10 years. That's when I was with my ex and my kids, and I stayed clean for a good while there. But he was an abusive [pause] mentally more — like, I could handle being hit, but not the mental abuse, which was a lot more than —*

Vera: So what happened?

Debra: *I just had enough. I just had enough.*

Vera: And he has custody of the boys now?

Debra: *Yeah. I wasn't married. I lived common law. I wanted my freedom. Still wanted my freedom. I find when you get married, you get a lot of your freedom taken away from you, so I chose not to.*

Vera: Hm.

Debra: *I don't know why I pick men like that.*

Debra: *I used to look after a friend when I lived in Calgary, and then when he died, they gave him a morphine drip, 'cause he was so sick. He was, like, 90 pounds, and he was, like, 6 foot. So it was horrible.*

Vera: And you cared for him all that time?

Debra: *Um-huh. And then he was stubborn. It was, like, he wanted to do things, like the dishes, and that was my job, and he would get mad at me and lean his head against the cupboard, just to hold himself up and do the dishes.*

Vera: But, he wanted to do it.

Debra: *Yeah, he was very independent.*

Vera: So did you live with this friend at the time then?

Debra: *Yeah. [waitress interruption]*

Vera: So you've seen a lot [pause] of people dying.

Debra: *Seen a lot of deaths.*

to my mom and dad

"There is a constant recounting of places on the body where life has left its impact – the scars, the locations of pain, the disfigurements, the amputations, the muscles and joints and bones that remember. There are the constant social rituals of placing people [...]"

(Stewart, 1996, p. 148).

Debra: *A lot of people are — I get upset when they bad-mouth their parents. I'm saying, "You're really lucky to have parents." It really hurts me when they talk bad about their parents, 'cause I wished that I had that.*

Although Debra continues to have occasional contact with her parents, the experience of her mother being either absent or inaccessible for her has shaped much of her relationship with her mother and early childhood stories. The absence of close relationship bonds as a child, as well as parental alcoholism, and homelessness, makes it difficult for people to make sense of their identity (Weiser, 1993). As well, the absence of her parents and other close relatives in her life left Debra marginalized and bereft of a social support system that could help her deal with her diagnosis as HIV positive.

broken homes, broken hearts and broken links of community

attentive~bountiful~caring~devoted~encouraging~famil
iar~gentle~hope
ful~kind~loving~motherly~
nest
led~open~protective~querulous~reward
ing~seen~tend
er~unfaltering~vital~warm~x~yummy~zeal
ous

a relationship that never was

a relationship whose loss Debra grieved long ago

Vera: Throughout the time, did you still keep contact with any of your parents? Or did you reconnect with your parents later on?

Debra: *Later on. We grew up in the foster homes. Mom was abusive. That's what I was told. I don't remember.*

Vera: You never have seen her?

Debra: *Oh, yeah, I've seen her. She's been to where I live now. But she was drinking when she came, so I didn't want her to stay very long. I just kind of told her I wasn't feeling very well and had to take my medication and go to bed. So she left. Must be hard on her, too, but she must blame herself, maybe. I don't know. If I was in her shoes, I would be blaming myself. If my kids grew up and something happened like this to them, I would be blaming myself.*

Vera: Must be really hard for you to see your mom now sometimes.

Debra: *Yes, she was very abusive. She used to pull my hair and do things like that. Or she used to — you know how little girls like to hang onto mother's legs? She used to kick us out of the way. She was just cruel. I just blocked most of it out. This is what my dad has told me, but I don't know what to believe from my dad any more.*

Vera: Do you remember your dad?

Debra: *Oh, yeah. I see my dad occasionally where I'm at.*

Vera: Was your dad abusive, too?

Debra: *No, my dad wasn't abusive.*

Debra: *My parents drank, so I switched to drugs instead of drinking. I don't like watching people drink, I just —. Because of my parents, I don't like how people act. They get angry. [break in conversation] when they have money, they drink, and they argue and they fight with each other.*

Vera: That's must be very stressful for you being around others who drink.

Debra: *Just makes the whole — everybody uptight.*

Vera: And I'm sure it brings back memories for you, too, like you said, with the drinking and your parents.

Debra: *Yeah, 'cause they never used to get along. They fought.*

Vera: Are your parents still together?

Debra: *No, not for a long time. My mom moved to a small town.*

Vera: A small town?

Debra: *Maybe she just needed to get away. Maybe there's memories here for her that [pause] might bring back hers, back here. I don't know. It would be nice to have her here. I would spend a lot of time with her.*

Vera: So you've grown a little bit closer to her, then, over time?

Debra: *Yeah. I used to hate her for everything, but she had problems, and I have to understand that. She had a drinking problem. Have to forgive her; she's my mother; she's all I have.*

(   )

4

Debra was diagnosed while in the hospital in 1998. Her dad came to visit her after she was told she had tested HIV positive, as did her mom. At the time Debra was in and out of the hospital a lot and traveled between living on the street or wherever she could find shelter and the hospital.

Debra: *Yes. He didn't stay very long when he came to visit me. It was, like, he felt that he had to. It was something that he had to do.*

Vera: So he felt obligated.

Debra: *Yeah.*

Debra: *My dad told my friends.*

Vera: Your *dad* told your friends?

Debra: *Yes, my dad told everybody he knew downtown that I knew that I had it, which I didn't think it was his place to tell.*

Vera: So you trusted him with telling him, and he went and spread —. What has that done to your relationship with your dad?

Debra: *There is none.*

Vera: Did anything change between you and your friends?

Debra: *Some of it did. They felt sorry for me, or — and I don't like people feeling sorry for me — or they just [pause] I don't know. With the working and doing drugs and stuff like that, they were very careful around me. They didn't know how to act around me.*

Vera: Did you find you had to educate your friends?

Debra: *Yeah. But it hurt me that my dad would do something like that when it wasn't his place to, especially when I didn't tell the person, and I was just partying with the person. My dad had no right. It's not like I was going to have sex with them or whatever. I was very careful of the drug use, used my own needles. My dad had no right. Now they're not my friends any more. They don't want to be around me. They don't want to get high with me. They're afraid that they'll get sick.*

Vera: So you lost some friends, too, because of that, then?

Debra: *Yeah. My mom was very caring when she found out. She probably told people that were close to her, which was okay with me, but she didn't do what my dad did. He told everybody that I know. Everybody that I know.*

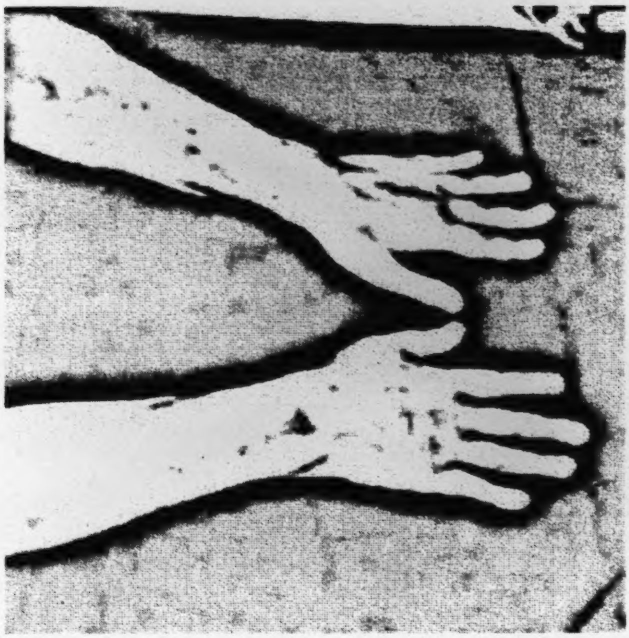
Vera: What was your mom's reaction when she found out, then?

Debra: *She was pretty sad. And she came to visit me, but she had to drink to come and visit me, and she didn't stay very long, because I don't like her when she's drinking.*

Vera: So that was just her way of coping with it. She'd drink and try and —.

Moneyham et al. (1996 b) examined the experiences of women infected with HIV when disclosing their HIV status. Unanimously the women expected and feared negative responses from others and discrimination. Confidentiality for these women was particularly important due to the associated stigmatization. Issues of confidentiality also kept women from using much needed services and resources. As part of the same study Moneyham at al. (1996 a) explored the perception of stigma in women infected with HIV. Themes representing different perceptions of stigma were identified. A main theme was 'distancing by others', which was most often attributed to a lack of accurate information. Because of the existing stereotype surrounding the transmission of HIV/AIDS such as promiscuity and drug use, women perceived that they were being blamed and therefore were uncomfortable in social situations due to the reactions of other people. Pity, another predominant theme, reinforced a feeling of being different for these women.

Since HIV is transmitted through blood and body fluids, it is often linked to venereal diseases and the ideas of pollution (Gatter, 1999), which leads to the discrimination of those who are HIV positive. Discrimination in the context of anxieties and fears at the community level is also of particular concern. Aboriginal peoples living with HIV have been denied housing and/or have been driven from their community by local authorities. Band councils governing aboriginal communities have the right through the Indian Act to override individual rights related to sexual orientation and HIV/AIDS confidentiality. Subsequently, people living with HIV/AIDS have to negotiate their private life in public and as a result instances of negative community reactions to people living with HIV/AIDS have been encountered by aboriginal men and women (Lambert, 1993; Crown et al., 1993).



to you my sister

Moments in our life history can sometimes be so distressful that they can neither be forgotten or remembered (Enriques, 1990).

Vera: Did you pick it up after you had your kids?

Debra: *No, I had to cook for my sister when I was younger, so —.*

Vera: Was your sister together with you in foster homes, or was that before that?

Debra: *One home.*

Vera: One home? Out of all the many homes you've been in, only one home you were together with your sister?

Debra: *Yeah. They split us up.*

Vera: Why?

Debra: *No room.*

Vera: No room? Are you still in touch with your sister?

Debra: *No, she committed suicide.*

Vera: But did you stay in touch before she committed suicide?

Debra: *Yeah.*

Vera: So was she the closest family member you had?

Debra: *Um-huh.*

Vera: That must have been really difficult, always in different homes, different places. Did they give you a chance to be together?

Debra: *I can't remember.*

Vera: You can't remember.

Debra: *No.*

Vera: What was your sister's name?

Debra: *S.*

Vera: S., was she your only sister?

Debra: *Yeah.*

a postcard from my past

spaces of desire and apprehension

For Debra, making sense of her life meant having to connect her personal stories to larger social, cultural, political and economic issues. Sometimes Debra saw these connections so clearly. The word foster home became synonymous with the word displacement and being different. She cannot recall a home where she received the attention or love she longed for …

dismembered
remembered
relationships between

Debra: *I've been in 15 homes. That's the child welfare system for you. I've thought of suing them, because I maybe would have a different life. You never know. The way that I am, I think I would be different. If I'd had somebody to love me, I would have been different.*

Vera: Did you stay with anybody for very long, or was it all very short?

Debra: *Yeah. Or I'd run away, or they're abusive, too. Some of the homes were abusive. So if a good home came along, I wouldn't know.*

Debra: *There's one guy there right now where I am staying that's cross-stitching. I do that. I do the same thing: cross-stitch or crochet. I've done that. When I was younger, getting locked up, that's what I learned to do, was to do needlepoint. When I was locked up, see?*

to my sons

Debra: *I smudge sometimes by myself when I'm not feeling so strong. When I'm not feeling so strong, I got some sweetgrass. I pray myself that I'll be okay.*

Vera: That is good, because it does help you to stay strong.

Debra: *I have to. I can't give up right now. I still have two kids. [pause] But I've always been a fighter. I've never really given up. Many times I could have given up on my life, but I haven't.*

Debra has two teenage boys, who are 13 and 9 years old. She talks about them a lot and her whole face lights up with a radiant smile when she does. She was with them when they were smaller, but not now. It's been difficult for her to even see them, because they live in a different city with her previous common-law partner. The last time she saw them was in 2001, it must have been September or October. She talked about how big they had grown, and how well they did in school, what they like and how they relate to each other. She knows it has been hard for them not having her around.

Vera: Well, that'll be nice to get something for your boys. Do they usually send you card for Christmas?

Debra: *They got me a gift last year, a foot care kit. A really nice one from The Body Shop.*

Vera: Wow! Did you use it?

Debra: *I used part of it. I saved most of it, though, so that I can look at it. It was nice.*

Vera: They must miss you.

Debra: *Yeah. Yeah. It's hard on them. They wish I was there [pause] just watch them grow up [pause] see what they do and the things they like to do. They'd really love to show me, but they can't.*

And there were times when it was difficult for Debra to make contact

Vera: Have you heard from your boys?

Debra: *I tried to phone them the other day, but they weren't home. The ex hung up on me. He said they were spending Christmas somewhere else, so I won't be able to get a hold of them.*

Vera: I just thought maybe you got in touch or something. As you're moving, they probably do like to know where you're at, at least.

Debra: *They don't call me anyways when I tell them where I'm at. That's something to do with dad, I'm sure.*

[...]

Debra: *Um-huh. Yeah, that was the hard part of Christmas, not being able to talk to them.*

Vera: It must be difficult, because when they hang up, you can never explain.

Debra: *Yeah. Should I phone back and try again. And all I know is they're just going to hang up again or not answer. So why should I set myself through that pain?*

Vera: [pause] Do you do a lot of cross-stitching, then, when you're by yourself?

Debra: *Sometimes I don't have the concentration to do it. I'm thinking about other things. I think about my kids a lot. Especially when I get sick, like with the flu or stuff, I get really scared that maybe I'm going to get sicker, because of the TB, and I'm coughing. I get scared, 'cause there's another fellow that got the flu while I was there, and he ended up in the hospital. He's in the hospital right now.*

Vera: Have you told your boys at all that you are sick?

Debra: *They think I have cancer.*

Vera: Okay. Is that what you told them?

Debra: *I don't know if my father told them that I was sick with HIV or if I was sick with cancer. I don't know. But my son, I asked him, and he thinks I'm sick with cancer. I could never tell them that I'm sick with HIV. I could never. It would never happen, not on my side, anyways. Because I have two boys that don't know that I'm sick.*

Debra: *I thought I'd know all the right things to do from all the wrong things she did, but I couldn't do it. I couldn't. So maybe I was just too young to have children.*

Vera: Yeah, you were very young, weren't you? [waitress interruption] Having kids so young does make it hard, doesn't it?

Debra: *Yeah. Or maybe I wasn't ready to be a mother at all, because I have so much going on in my own life, that I have to take care of my own stuff.*

Vera: Hard to know what's right and what's wrong at the time.

Debra: *Now I wish I could change everything, but I can't. I just got to go forward. Make changes. Even now I couldn't be a mom right now. I'd like to be, but I was never taught properly, so I'm not — I thought, well [pause] how do I say this? [pause] Not treat my boys the way that my mother treated me, that would be a change to being a good mother. But still you need family, extended family, like aunts and uncles, and I don't know if I have any.*

Vera: So you don't have the support, you feel, around you, that can help you.

Debra: *Yeah. I don't know, when I do pass away, how many people would actually be there for me. Maybe that's why sometimes I do drugs, because I want to just forget, because I put a wall around myself and I don't have to think about anything except for the drugs. No, it would be bad for the kids, because I'd be there for a little while, and then I'd be gone [pause] And I miss my boys.*

Vera: Oh, you must miss them so much.

Debra: *I do. I miss them a lot.*

surviving

“The knowledge of my abuse has come to me in the form of
dreams,
body memories,
feelings,
compulsive behaviors
and
physical ailments”
(Levey, 1991, p. 46).

Debra: *And even to tell the father of my children, 'cause he knows of my past. Before, he used to call me a hooker, and that I had HIV when I didn't even have HIV at that time. Then when they told me in the hospital, I just [pause] it just blew me away. I freaked out. I just couldn't believe it was me. I had a friend that had died of it before, so I know what it's like to die with HIV, and I don't really want to die that way. I guess I have no choice now.*

For Debra a HIV-positive diagnosis is strongly linked to death, dying, and the disruption of her life. Her diagnosis heightened her degree of uncertainty and introduced tensions she had not experienced before (Crossley, 1998). After having being diagnosed for three years, she recognized that she has not yet come to accept her diagnosis. For Debra it was troublesome to talk about her HIV positive status, she was often counting the years, the years her friends had lived, the years since she was diagnosed and the years she might still live comfortably. It wasn't so much death she feared, as is the process of dying itself. Most of all she is afraid of dying alone and of the physical process of dying. Having seen people die of AIDS was frightening to her, since most of her friends who had died, died in the midst of adulthood, in pain and agony, leaving children and friends behind.

As much as Debra knew about the fearful things which might lie ahead, she knew too there were things she could do to remain healthy, to enjoy her life to the fullest in the moments that still remained.

Just prior to her diagnosis Debra had been in and out of the hospital on several occasions for substance related problems. Each time she was released out onto the streets, at times not knowing where she would stay. It wasn't until she was diagnosed with HIV that care providers paid attention to her psychosocial needs and secured housing for her prior to her discharge.

Debra doesn't remember the circumstance of her initial HIV test or the test to confirm her HIV positive status. She doesn't recall anyone taking the time to explain what the results really mean. Maybe everyone assumed because she was aboriginal, female, a substance user and working in the sex trade that she already knew all there was to know or maybe nobody cared. Like other women, Debra was expected to learn about the disease on her own, to change her sexual and substance use behaviours, to participate in treatment and to improve her health habits (Stevens & Doerr, 1997) without much support. By being inattentive care providers reinforced Debra's initial perception that she was to blame and accept personal responsibility for her HIV positive diagnosis (Lawless, Kippax, & Crawford, 1996). The reinforced feeling of guilt and shame, in addition to the cultural barriers for aboriginal women continue to deprive aboriginal women of much needed resources to maintain and improve their health (Ship & Norton, 2001).

Debra: *Yeah. I went back out onto the street, and I went back into the hospital, and I went back out onto the street again, and I went back into the hospital, and then I went to this house where people who are HIV positive, or people with AIDS live. The hospital kept on releasing me to the street 'cause they had no place for an older woman that's been on the street. They have nothing. They have nothing for the older women that are trying to change their life. They think that once they're going to be that way, always; that they'll never change. But, there are some that do want to change. So they sent me from the hospital to the house, and I was 90 pounds when I went there. So I've put on quite a bit of weight mostly because of that drug called Cyprexa®.*

Vera: Weight gain is one of the side effects of Cyprexa®.

Debra: *Yes, and I didn't know that, and they put me on that when I went to the House, 'cause I was so small. They put me on that drug, and they should have stopped when they seen me gaining. When I was getting around 150, they should have stopped it right there, but no, they let it get right up to 190, and then I didn't feel good about myself. Then I want to go out and use because [pause] you don't want to eat and you just use for a couple of days and you walk around, and your metabolism is just go-go-go, and you lose weight right away.*

Vera: Right. Which is not good for you, because you're on all the HIV meds now, and you probably don't take your medication with you when you go out, or?

Debra: *No. I'm going out tonight, but I'm taking my meds with me. I'm taking them. I* *take lots of medication. I take some at night — when I go to bed, maybe 14 to 16 pills at night, and when I wake up in the morning, about 10 pills. And throughout the night, every 4 hours. I take something every 4 hours. Morphine every 4 hours. If you know anything about MSCont, I take 300 milligrams three times a day, which is a big dose. And some days I feel it's not enough.*

Vera: Do you find you still have a lot of cravings?

Debra: *Sometimes I do, yeah. It's a different life, because I don't [long pause] I have no family here. Sometimes I go to this place downtown. Well, that place is like [pause] it was just a place I hung around with people, and it was a place people knew me. Just like on TV, like that show "Cheers" or whatever, where people go to the bar and they all know each other? It's the same thing as when I go to this place; it's the same thing. A lot of people know me. And when I get thin, they think I'm going to die. When I get thin, I get worried, too, maybe it's my time is up to die, or when I get sick like I did last week with the flu, I thought I had pneumonia, and I had bronchitis. When you get sick like that, it's very worrisome. 'Cause I also have — they found some spots on my lungs. I've been exposed to TB, so that I need to be on medication for that, and I haven't been on medication yet. So they're just working on what medications to put me on. And then I have Hep C and your liver is fighting all the time, and then you've got all these medications going through your liver.*

Vera: It must be difficult. Do you feel tired a lot?

Debra: *Yeah, I'm tired a lot. They think it's depression at the House. I think it's a little bit of both. They want to put me on a methadone program, but I've been on the methadone program before, and I really didn't like it. They still talk to me about it a lot, and I still say, "No, I'm not ready." And you can't just take somebody that's been on morphine for a long time and say, "No, you can't have it any more." Your body needs that.*

Debra was very proud of her new home, not only was it the most stable place for her in years, but she also had her very own room, a large TV she had bought with the money she had been saving, and she met people she felt genuinely cared about her. She was hopeful that she could come to terms with some of her life experience here and was looking for a counselor who was willing to work with her over an extended time period. The one part that was very difficult for Debra in her new place was to see people die or be hospitalized for extended time periods.

Debra: *Yeah. So then since a friend of mine died, I kind of [pause] how do I say? — not get so close to people now? Because I don't want to get hurt any more.*

Although Debra often talked about being lonesome at the place she was at she was well aware that without the stable home she would most likely return to her substance use, sex trade work and not taking her medication. Unfortunately, Debra was asked to leave just prior to Christmas, because she and a fellow resident and his family had developed a close relationship. The relationship in the eyes of the staff was harmful to Debra and she received a warning and a request to discontinue the relationship, which she disregarded.

Debra: *That was their program, and they didn't care whether I had a place to go or not. and I was really hurt. I was scared. Now my probation officer doesn't like where I'm living, right downtown, so I don't know what she's going to — if she's going to approve the place or not. If she doesn't, I don't know what I'm going to do. I guess I just have to talk to her and say, "Listen, I'm looking for a place, going to Capital Region Housing, and just give me this time to find a place of my own." That's all I need. She goes, "Well, are you doing any drugs?" I said, "No." I said, "I've been tested by the doctor. I got a constable watching out for me." She says, "You been on the street?" I said, "No, I haven't been doing anything," which I haven't been.*

Debra was distraught over having to leave her stable home. She had a difficult time sleeping and eating. Amazingly we continued our almost weekly conversations, although often they were very brief. She found friends that would help her move and was able to move in with some acquaintances. However, she continued to ask if she could move back to her previous residence and was willing to obey to their rules.

Debra: *They said if I did some kind of program — was I willing to do a program. I said yes — for me to stay — so they got my hopes up. Then they had another meeting, they said no. So I was hoping that. They had my hopes up, and then they brought my hopes down again. You can't play with a person like that. The Sober Club, they did a prayer circle for me, where they — with my heritage, did a smudge with me, and helped me out a little bit, give me some strength and hope. They brought some of their friends in, just to make the circle stronger. I just wanted to — you know. And they're supposed to be Catholic people — Catholic Social Services. That's why I have a hard time believing in God sometimes, because of things like this. But someone told me that my Creator didn't make no junk, I'm someone special. So I'm supposed to remember that. A friend told me that. In fact, she said to keep remembering that, "I'm somebody special." It'll keep me going; it kept me going. 'Cause I could just throw my hands up and give up and say, "This has happened to me too many times. What's the use?" But I'm* *still fighting it. Helps me not think about — since I'm right down on the main drag — helps me [pause]. And all that, scared of going to jail. That's my biggest fear. I don't want to go there, 'cause they'll take me right off methadone. Then I'll be hurting even worse than I am right now.*

but sometimes I wonder when is it going to stop?
when is it going to stop?
when am I going to have to stop fighting,
and when are things going to start to come easier for me?

Debra lived in one of the roughest apartment buildings in the city, a lot of people in the building were drinking, used other substances, or were fighting at all times. During Debra's time in the building a murder was committed just down the hall. Debra stopped taking her HIV meds soon after she moved in, because she felt hopeless and wondered why she would want to prolong her life? However, others were concerned about her and told her doctor that she wasn't taking her medications.

Debra: *The lady that lives there has the same doctor, and told the doctor I wasn't taking my medications, and he got upset. They were delivering to me, and then he said, "No, you have to go get it now. So hopefully, when I go see him next week, he'll put it back on delivery. But he got — he was really upset when he found out that I wasn't taking my meds, 'cause I'm undetectable now, which is a really, really good thing.*

In the past Debra's response to stressful situation or moments of isolation from others was to get high …

(un)belonging
(un)relatedness
(un)familiality

Debra: *You know, there's a lot of problems I have. Like, the drug problem, and not — I isolate myself quite a bit.*

Vera: Do you?

Debra: *Oh, yeah. I feel more comfortable that way. Once in a while, I twist off. I need to do something. I've been doing it for 15 years. Yeah, so to stop all of a sudden is not practical. It doesn't happen that way. I do my thing, whether it hurts me or not.*

Vera: You must still know a lot of girls downtown.

Debra: *Oh, yeah, I know lots of girls. They're something like family. That's what I call my family.*

Vera: I'm sure there's been a lot of girls who have been there for as long as you have.

Debra: *Yes.*

Vera: So you do get *very* close.

Debra: *Yeah, we sure do.*

Debra: *Last time I used I got an abscess. Now I feel like I don't want to use for a while, if that's going to happen. I don't want to do it. Hurts too much. I've had them before, but you always forget what that pain is until it comes around again, and then you recognize it. I was putting hot compresses on it at first, and that was coming to a head where it was going to probably open on its own, but I couldn't take the pain any more. It's just I wish there was different ways of dealing with my pain and my hurt, that I'm hurting myself; like, physically hurting myself. I wish there was different ways for me to deal with it. I just don't know.*

Vera: Have you ever tried a different way?

Debra: *[pause] I don't think so.*

[…]

Debra: *I think that's what happened. Things were just — they were bothering me, and that's how I dealt with it. Got to find better ways to deal with it, I guess.*

Vera: What do you think better ways would be?

Debra: *I don't know where I would be. I would probably be doing it right now.*

Debra's life had always been very complex and amidst moments of isolation and separation were also moments of closeness and hopefulness. Debra was beginning to explore her aboriginal culture a little bit more and began to seek out elders for help. However it was still very tentative. She also began to participate in an aboriginal group meeting to talk about HIV and the needs of aboriginal peoples with HIV.

Debra: *Your spirituality. You've got to be very strong. I think I need to do a sweat. [break in conversation] and you go in, and they put rocks on every time you go in. The more sin that you do or the more that you feel bad, is the more you suffer. But I know I'm — in my heart, I know that I'm a good person. I just need people to see that.*

Vera: Have you gone to a sweat, ever?

Debra: *I've gone to one. I haven't gone to one for a while. But I would like to sure go for another one. I think it's about time that I did that, or go see an elder. There was an elder that used to come and see me while I was in the hospital, and we'd go down and do some sweetgrass.*

Debra also connected with some service providers that helped her find a place at a shelter, provided some resources like food, car rides to doctor's appointments, and money in return for taking her HIV medications. Debra was always very hesitant to connect with new service provides, fearful they too would make demands she could not meet, judge her for her substance use, or discriminate against her based on her HIV positive diagnosis.

Informal social networks in the inner city are often well established and integrated. At times social networks provide people with critical information about which social workers to talk with, how to avoid difficulties at shelters or help people locate resources such as food (Wagner, 1994). At the same time that social networks can be helpful, there are expectations that all personal resources should be shared, regardless of the tension and adversity it adds to peoples lives.

Debra: *Like, last night, they made me walk to Mohawk to get change for them so they could buy beer off my money, saying I owed them money, and they wouldn't leave me alone until I went, and I was not feeling well. I had to get a ride home with this total stranger to my house, 'cause I couldn't walk back. And then I gave somebody my bank card to go to the bank to get money for me, and they took my bank card and they deposited it in an empty envelope for $500, and tried to take out $500 from my bank account. So they want to close my account. [pause] So some friends, they're not kind people; they're not my friends, they just use me.*

Vera: That's hard when you find that out.

Debra: *And then I want to hide everything all the time.*

Debra: *And I can't find my phone book. I lost my phone book.*

Vera: Oh, no.

Debra: *Yeah. Now I wrote your number down. This week I have it, but I need it for her, 'cause she's got all my things.*

Vera: And all your friends are probably in there, too. You had it at first, didn't you?

Debra: *Yeah, I just lost it in the last couple of days. Nobody seems to know where it went. It was just sitting on the kitchen table last time I seen it. [pause] eh. So fine. Sometime later, I had gone out for something. I wore a different jacket, and I went to the pocket, and there was this piece of paper with the phone numbers I had written on it. And I never wore this jacket. It was somebody else's. So he's trying to keep me there or something.*

Debra: *[pause] They are afraid I'm going to buy drugs and they're not going to get any and the other day they asked me for more rent. They want more money out of me. It's just, like, no, they're not going to get it. And then they are drinking and fighting, and I got —They bug me, too, all the time, why don't I eat, I never eat anything, I'm lazy. Well! Why should I do your dishes and clean your house when I got this little area I keep to myself? Constantly like this, on my back. On my back, all the time. So this morning, I just had it. I told them right out, I said,* *"Fuck right off." I said, "I've had enough." "Oh, your suitcase will be in the hall." If it is, the cops will be down, 'cause I don't deserve that.*

Debra: *And they tried to get me to do drugs so then I'll go out to work, right? They'll try and get me started, and then off I go.*

Vera: They know that. They know that circle.

Debra: *So I didn't go out to work last night. That's why he's mad, he's calling me lazy.*

Eventually, Debra moved into a shelter, where at least "you have a bed and locker, and are out of the snow". This is where she connected with one of her previous boyfriends.

Debra: *Yeah. So I don't think I'll be going back there tonight. I think I'll be going with M.*

Vera: M's okay with, to you?

Debra: *I think so. When we went together, we used to fight all the time 'cause he's a very jealous person. He thinks I'm going out with everybody. So hopefully, he's not like that. He just bought a brand-new truck yesterday. He phoned my dad, and my dad gave him the number to where I was. If M. sees me, he says, "Are you doing drugs?" I says, "No," which I lied, because I did smoke some. And I got to be honest with him, tell him what's going on and tell him why. I'm stressed out, I've got to do something. Yeah. He's just so [pause] that's why I'm so scared of him sometimes, 'cause he's so obsessive and he gets jealous really easily. Got mad at him this morning, 'cause he thought I was there at the bar drinking, and I thought, "I'm going to see Vera tomorrow. Why would I be at the bar drinking?" I haven't drank through all of this.*

Debra: *He says, "Are you still mad at me?" I said, "I'm a little bit hurt that you don't trust me or believe me when I say something. I have no reason to lie to you." If I want to go out and do something, I'll go out and do it. No one's gonna stop me. If I was going to do something, it would have been already. I'm really sure of that. If I was going to do anything, it would have been already.*

M. wanted to find an apartment together with Debra, but Debra continued to be hesitant and was thinking a lot about finding her own space.

Debra: *Yeah, to tell him that. No, I need my space right now. It's the first time I've been — actually, if I do get an apartment — all on my own for a long time. He says to me all the time I scare him. "What do you mean, I scare you?" He says 'cause he's got clean and sober over time, he doesn't want to mess that up. He gets upset really easily. Even in traffic, he gets upset really easy. He's a very touchy person. And then I feel like I've just got to walk on eggshells, and I don't want to feel like I have to go through that. I was hoping to see more change in him. I see some change in him.*

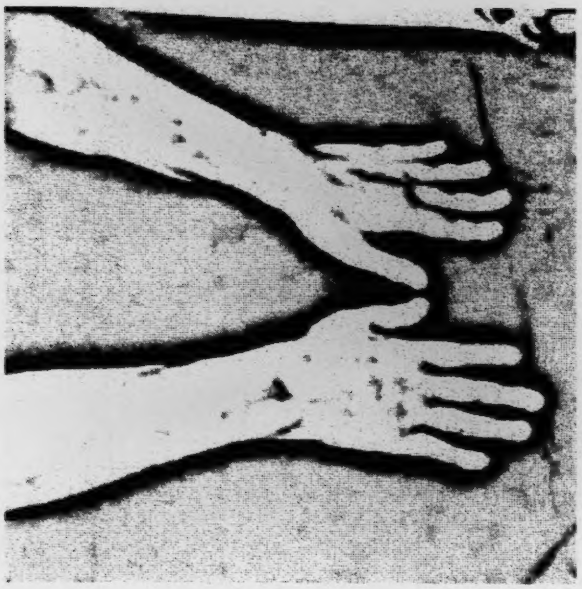
Debra: *He doesn't want to hurt me, I know that. He doesn't want me to — even when I cry, he gets really upset when I cry.*

Vera: Does he?

Debra: *Yeah. So I know he doesn't want me to be hurt. [pause] He doesn't ask — since all this happened, I got a little bit harder. I haven't really cried. Like I should do, have a really big cry, but I really haven't. I feel different. Like, I feel a little bit harder. I don't want to be that hard. So things'll start getting easier for me.*

And he thinks that — he says, "I have no money." I says "I don't care if you have any money or anything. I didn't phone him up —. I've had money in the past and it didn't make me happy, you know. Just need someone there that's understanding and trusts me.

So I think — I'm sleeping a lot. I think I have to be put on that anti-depressant. Everything is too much for me right now. Like, I'm so overwhelmed, I'm just tired all the time.



some other postcards

I worry about the scars on my arms, you know.

He told me not to worry about it, that he doesn't see that.

Debra wanted to make sure that I knew there was more than one way to tell, see and read her story. She worried how people would react to her story, would they see her for who she was or only for what she did? In retelling Debra was reminded of moments that she had tried so hard to forget, yet there were also those moments of joy and fun. Debra wanted her story to be one of possibilities, so young girls and women could see that they could overcome obstacles and make sense of their lives in spite of everything.

Debra: *Yeah. Yeah, I am. I just want to get this thing going smooth, really smooth, and talk about good times and not always bad times.*

Vera: I bet. You must be really afraid when that happens. [pause] And if it's such a close community downtown where everybody knows you, and your dad just tells it to one friend, you can see how everybody would know at the end.

Debra: *Yeah. They would call me a junkie whore with HIV.*

Vera: Really?

Debra: *Oh, yeah. As if I wasn't good for nothing else. And I want to prove to people that I am going to be somebody else in the time that I have left.. I have been wanting to record my life story for the last 10 years. I been wanting someone to do what you're doing with me. My story might take a little bit longer than [pause] than [pause] most. I'm starting thinking, and I get sad when I think about certain things. And I want to be able to [waitress interruption] It's the first time I get to tell my story ...*

Vera: Really?

Debra: *I want to prove to people that I am going to be somebody else in the time that I have left. 'Cause it's up to 10 years, I think. Some people live past 10 years, though.*

Vera: We will have to work hard to get your story right.

Debra: *Do you think you could put my story into [pause] I don't know [pause] in different [pause] I don't know. Like, it just jumps around a lot. Would you be able to sort that out?*

Despite Debra's wish to tell all of her story, it was hard and many of our conversations consisted of half spoken stories and sentences. I was often thinking of "how careful she has been to leave out anything painful; but her sense of solitude is profound and it surfaces, unwillingly, several times in her brief text, which ends in mid-sentence" (Behar, 1996, p. 95).

Debra: *Sometimes I don't like talking about —. You see when I'm talking and we talk about it, and I talk about something else.*

Vera: Yeah, it must be really hard.

Debra: *Yeah. I'm very [pause] like I said, I isolate myself a lot. I'm very — I guess a loner. I don't like to talk about my problems. Because I wouldn't want to sit and listen to somebody that had a lot of problems. That would kind of make me depressed, so I really wouldn't want to depress anybody.*

Debra had a beautiful smile, but I have no memory of ever looking at her without at least glancing once in the midst of our conversation at her arms and so I could not look at her without sadness. Yet, there were so many moments we talked about ordinary events, place and people about the love for oranges and the caring for friends:

Debra: *So I went and I bought a box of oranges. I love oranges.*
Vera: Oh, that must have been good!
Debra: *And just milk and eggs and things. But she's older, eh, so I got to take care of her a little bit. I don't eat eggs, but I bought them, just for her.*
Vera: That's good. It's nice to get the oranges before Christmas.
Debra: *Yeah. I love 'em. I could eat a whole box.*

about biting nails and false teeth:

Debra: *I used to bite them really bad, but now that I have false teeth, it's hard to bite. But still, you can bite them. I don't wear them when I'm at home. I take them out. Everybody says I look funny without them in, but I'm more comfortable with them out. You don't get permanent liner until a year after they get done, so they slip and slide all the time for a year.*
Vera: But yeah, I guess false teeth would help with not biting your fingernails.
Debra: *But it'll be nice once they grow a little bit. I'll shape them. Some ones are strong, but the other ones, they bend. Like, when you push down on them, they kind of bend. They're not that strong yet.*

and then there were the conversations about dreams and hopes:

Debra: *Sometimes I want to cry and I don't. It's almost like I'm just lost since I've come to Edmonton, I've hardened up quite a bit. When I was in Calgary, I still had needles, and I picked fights and stuff. Now, it just gets to about here, and then I can just swallow it and it goes away. But I guess it doesn't really ever go away.*

Vera: Why has that been different? Do you know?

Debra: *Just maybe being alone and [pause] and [pause] just thinking about my life and where it's started and where it's got me so far, and where I want to be. So I got to fight. I really got to fight hard.*

Vera: Hm.

Debra: *That's why they want to get me into talking to younger girls. I'd like to do something like that. It would be good for me, also. I hope to, one day.*

Vera: That would be really good.

Debra: *Like, the schools. Maybe scare them a little bit, frighten them, and then maybe they won't do it. Yeah. So I think it's about time I changed, and help other people.*

Vera: Yeah. Yeah. That would be good, but like you said, sometimes it's also really hard to tell your story, because you always relive it a little bit, don't you?

Debra: *Yeah. Think about a lot of things and I can replace a lot of things, but I can't replace my life.*

Debra: *Yeah, I really hit bottom there. But I had to phone and let you know that I was okay.*

Vera: I really was worried about you and I was just so relieved when you called me.

Debra: *You get close to people. I've grown quite close to you.*

Vera: I always look forward to talking with you.

Debra: *Yeah, me, too. It's amazing that I can still feel.*

Vera: Yes. Yeah. No, I think that's kind of [pause] you know. It tells a lot about where you've been and where you still are.

Debra: *Hopefully, it'll change. Like, after I get better, I'll get successful at something. That would be really important to me, just to show people that people can change.*

Throughout all our conversations Debra and I have grown really close. I worried a lot about her and although we often talked about the scars on her arm I never lost sight of her talent, creativity, gentleness and fight. Debra was able to make me part of her story and to live and breath with her for brief moments.

a postcard from a friend

My dearest Debra;

Last night I dreamed about you and when
I woke up in the morning I got up to write
to you again. I just wanted to let you know
how much our friendship means to me.
Be assured that wherever you go and
Whatever may happen to you in your life
journey you will always be in my thoughts,
and my heart.
I know you will be present in my life when
I talk to the children around me and when
I work with women on the streets and in
their homes … you have taught me so much
about patience and persistence and perseverance,
too.

Alles liebe, Vera.

For Debra

Abrums, M. (2000). "Jesus will fix I after awhile": Meanings and health. Social Science & Medicine, 50, 89-105.

Acker, J., Barry, K., & Esseveld, J. (1983). Objectivity and truth: Problems in doing feminist research. Women's Studies International Forum, 6(4), 423-435.

Adams, A. (1948). Camera and lens: The creative approach. Studio laboratory and operation. Boston: New York Graphic Society.

Anderson, K. (2000). A recognition of being. Reconstructing native womanhood. Toronto, ON: Second Story Press

Arielle Matiss, I. (2001). Moments in time. In A. L. Cole & J.G. Knowles (Eds.). Lives in context. The art of life history research (pp. 223-229). Walnut Creek, CA: AltaMira Press.

Ayers, L. & Poirier, S. (1996). Focus on qualitative methods. Virtual text and the growth of meaning in qualitative analysis. Research in Nursing & Health, 19, 163-169.

Bach, H. (1998). A visual narrative concerning curriculum, girls, photography etc. Edmonton, AB: Qualitative Institute Press.

Baldwin, J. (1955). "Many thousands gone" in his notes of a native son. New York: Bantam, p. 18-19.

Ball, M. & Smith, G. (1992). Analyzing visual data. Newbury Parks, CA: Sage.

Bateson, M.C. (2000). Full circles overlapping lives. Culture and generation in transition. New York: Random House.

Bateson, M.C. (1994). Peripheral Visions. Learning along the way. New York: HarperCollins Publisher.

Behar, R. (1996). The vulnerable observer. Anthropology that breaks your heart. Boston: Beacon Press.

Berger, J. (1977). Ways of seeing. London: Penguin Books Ltd.

Bergum, V. (1999). Ethics as question. In T. Kohn & R. McKechnie (Eds). Extending the boundaries of care (pp.167-180). New York: Oxford.

Berman, L. (1996). Beyond the smile. London: Routledge.

Bhabha, H.K. (1994). The location of culture. London: Routledge.

Bruderle, E. & Valiga, T. (1994). Integrating the arts and humanities into nursing education. In P. Chinn & J. Watson (Eds.), Art & aesthetics in nursing (pp.117-144). New York: National League for Nursing Press.

Boud, D. & Walker, D. (1998). Promoting reflection in professional courses: the challenge of context. Studies in Higher Education, 23(2), 191-207.

Bunting, S. (1997). Applying a feminist analysis model to selected nursing studies of women with HIV. Issues in Mental Health, 18, 523-537.

Cajete, G. (2000). Indigenous knowledge: The pueblo metaphor of indigenous education. In M. Battiste (Ed.). Reclaiming indigenous voice and vision (pp.181-191). Vancouver, BC: University of British Columbia Press.

Clandinin, D.J., & Connelly, F.M. (1988). Studying teachers' knowledge of classroom: Collaborative research, ethics, and the negotiation of narrative. The Journal of Educational Thought, 22(2A), 269-282.

Clandinin, D.J., & Connelly, F.M. (1994). Personal experience methods. In N.K. Denzin and Y.S. Lincoln (Eds.). Handbook of qualitative research (pp. 413-427). Thousand Oaks, CA: Sage Publication.

Clandinin, D.J., & Connelly, F.M. (2000). Narrative inquiry. Experience and story in qualitative research. San Francisco, CA: Jossey-Bass.

Cohen, F. & Durham, J. (1993). Women, children and HIV/AIDS. New York: Springer.

Cole, A.L. & Knowles, J.G. (2001). Lives in context. The art of life history research. Walnut Creek, CA: AltaMira Press.

Collier J. & Collier, M. (1986). Visual anthropology: Photography as a research method. Albuquerque, NM: University of New Mexico Press.

Connelly, F.M., & Clandinin, D.J. (1990). Stories of experience and narrative inquiry. Educational Researcher, 19(4), 2-14.

Cooper, J.E. (1991). Telling our own stories. The reading and writing of journals or diaries. In C. Witherell & N. Noddings (Eds.). Stories lives tell: Narrative and dialogue in education (pp. 96-112). New York: Teachers College Press.

Crossley, M.L. (1998). Women living with a long-term HIV positive diagnosis: Problems, concerns and ways of ascribing meaning. Women's Studies International Formum, 21(5), 521-533.

Crown, M., Duncan, K., Hurrell, M., Otoova, R., Tremblay, R., & Yazdanmehr, S. (1993). Making HIV prevention work in the north. Canadian Journal of Public Health, 84, Supplement 1, S54-S58.

Cruikshank, J. (1998). The social life of stories: Narrative and knowledge in the Yukon Territory. Vancouver, BC: University of British Columbia Press.

DeMarco, R., Miller, K., Patsdaughter, C., Chisholm, M., & Grindel, C. (1998). From silencing the self to action: Experiences of women living with HIV/AIDS. Health Care for Women International, 19, 539-552.

Denzin, N.K. & Lincoln, Y.S. (2000). Introduction. The discipline and practice of qualitative research. In In N.K. Denzin and Y.S. Lincoln (Eds.). Handbook of qualitative research (2nd ed., pp. 1-28). Thousand Oaks, CA: Sage Publication.

Devault, M. (1990). Talking and listening from women's standpoint: Feminist strategies for interviewing and analysis. Social Problems, 37, 96-116.

Dion Stout, M., & Kipling, G.D. (1998). Aboriginal women in Canada: Strategic research directions for policy development. Accessible: http://www.swc-cfc.gc.ca/publish/research/abwom-e.html

Dion Stout, M., Kipling, G.D., & Stout, R. (2001). Aboriginal women's health research synthesis project. Final report. Ottawa, ON: Centres of Excellence for Women's Health.

Dominguez, L. (1996). The lived experience of women of Mexican heritage with HIV/AIDS. Unpublished doctoral dissertation, University of Arizona.

Donnell Connors, D. (1988). A continuum of research-participant relationships: An analysis and critique. Advances in Nursing Science, 10(4), 32-42.

Eisenberg, E. M. (1998). From anxiety to possibility: Poems 1987-997. In A. Banks & S. Banks (Eds). Fiction & social research: By ice and fire (pp. 195-203). Walnut Creek, CA: AltaMira Press.

Emden, C. (1998). Conducting a narrative analysis. Collegian, 5, 34-39.

Enriquez, M. (1990). The memory envelope and its holes. In D. Anzieu (Ed.). Psychic envelopes. London: Karnac Books.

Ezzy, D. (2000). Illness narratives: Time, hope and HIV. Social Science & Medicine, 50, 605-617.

Farmer, P. (1996). Women, poverty and AIDS. In P. Farmer, M. Conners & J. Simmons (Eds.). Women, poverty and AIDS: Sex, drugs and structural violence. (pp. 3-38). Monroe, MA: Common Courage Press

Fine, M., Weis, L., Weseen, S., & Wong, L. (2000). For whom? Qualitative research, representation, and social responsibility. In In N.K. Denzin and Y.S. Lincoln (Eds.). Handbook of qualitative research (2nd ed., pp. 107-131). Thousand Oaks, CA: Sage Publication.

Gadow, S. (1999). Relational narrative: The postmodern turn in nursing ethics. Scholarly Inquiry for Nursing Practice: An International Journal 13(1), 57-70.

Gates, K., Church, K., & Crowe, C. (2001). Fidelity and ethical ideals. In A. L. Cole & J.G. Knowles (Eds.). Lives in context. The art of life history research (pp.152-163). Walnut Creek, CA: AltaMira Press.

Gatter, P. (1999). Identity and sexuality. AIDS in Britain in the 19d90s. London: Cassell.

Gillespie, N. (1995). One day at a time: Women's experiences of living with HIV/AIDS in low prevalence areas of the Midwest. Unpublished doctoral dissertation, University of Texas at Austin.

Gottschalk, S. (1998). Postmodern sensibilities and ethnographic possibilities. In A. Banks & S.P. Banks (Eds.). Fiction and social research (pp. 205-233). Walnut Creek, CA: Altamira Press.

Gullestaed, M. (1996). Everyday life philosophers. Oslo, Scandinavian University Press.

Gunn Allen, P. (1998). Off the reservation. Reflections on boundary-busting, border-crossing, loose canons. Boston, MA: Beacon Press.

Hall, J., Stevens, P., & Meleis, A. (1994). Marginalization: A guiding concept for valuing diversity in nursing knowledge development. Advanced in Nursing Science, 16, 23-41.

Hindeman, J.E. (1993). "I think of that mountain as my grandmother": Constructing self and other through landscape. Paper presented at the Annual Meeting of the Modern Language Association. Toronto, ON.

Hirsch, M. (1999). The familial gaze. Hanover, NH: University Press of New England.

Hirsch, M. (1997). Family frames. Photography, narrative, and postmemory. Cambridge, MA: Harvard University Press.

HIV/AIDS Epi Update (1998). AIDS and HIV in Canada (1998). Ottawa, ON: Health Canada.

HIV/AIDS Epi Update (2000). AIDS and HIV among aboriginal people in Canada. Ottawa, ON: Health Canada.

HIV/AIDS research priorities among aboriginal people in Canada (1999). Pan American Journal of Public Health, 5, 207-209.

hooks, b. (1995). Art on my mind. Visual Politics. New York: The New Press.

Jackson, L. (1997). Canadian federal government policies and the funding of HIV/AIDS community-based groups: Changing objectives in times of change. Canadian Review of Social Policy, 40, 19-45.

Knorr, K. (1996). Interview: Fetishism of black-and-white and the vulgarity of colour. In L.Heron & V. Williams (Eds.). Illuminations. Women writing on photography from the 1850s to the present (pp. 403-409). Durham, NC: Duke University Press.

Kuhn, A. (1995). Family secrets. Acts of memory and imagination. London: Verso.

Kuspity, D. (1996). Ana Mendieta, Autonomous Body. In Ana Mendieta. Santiago de Compostela: Centro Galego de Arte Contemporanea.

Laboratory Centre for Disease Control. (1998). EpiUpdate: HIV/AIDS epidemiology among aboriginal people in Canada. Ottawa, ON: Health Canada.

Lambert, D. (1993). AIDS and the Aboriginal community. Canadian Journal of Public Health, 84, Supplement 1, S46-S47.

Lather, P. (1986). Research as praxis. Harvard Educational Review, 56, 257-277.

Lawless, S., Kippax, S., & Crawford, J. (1996). Dirty, diseased and undeserving: The positioning of HIV positive women. Social Science and Medicine, 43, 1371-1377.

Leen, M. (1995). An art of saying: Joy Harjo's poetry and the survival of storytelling. American Indian Quarterly, 19(1), 1-16.

Levey, P. (1991). Self portraits. In J. Spence & P. Holland (Eds.). Family snaps. The meaning of domestic photography (pp. 46-48). London: Virago.

Lorde, A. (1981). The masters tools will never dismantle the master's house. In C. Moraga & G. Anzaldua (Eds.). This bridge called my back. Writings by radical women of color (pp. 98-101). Watertown, MA: Persephone Press.

Lorde, A. (1984). Sister outsider. Essays & speeches by Audre Lorde. Freedom, CA: Crossing Press.

Lowry, J. (1999). Photography, video and the everyday. In D. Brittain (Ed.). Creative camera. Thirty years of writing (pp. 278-283). Manchester, UK: Manchester University Press.

Maeve, M.K. (1999). The social construction of love and sexuality in a women's prison. Advances in Nursing Science, 21(3), 46-65.

Malin, J. (2000). The voice of the mother. Embedded maternal narratives in twentieth-century women's autobiographies. Illinois, CO: Southern Illinois University.

Marcenko, M.O. & Samost, L. (1999). Living with HIV/AIDS: The voices of HIV-positive mothers. Social Work, 44(1), 36-45.

Marmon Silko, L. (1996). Yellow woman and a beauty of the spirit. New York: Simon & Schuster.

Marmon, Silko, L. (1977). Ceremony. New York: Viking Press.

Matiation, S. (1999a). HIV/AIDS and aboriginal people: Problems of jurisdiction and funding. (2nd ed.). Montreal, QU: Canadian HIV/AIDS Legal Network.

Matiation, S. (1999b). Discrimination, HIV/AIDS and aboriginal people. Montreal, QU: Canadian HIV/AIDS Legal Network.

McBride, A. (1993). From gynecology to gyn-ecology: Developing a practice-research agenda for women's health. Health Care for Women International, 14, 315-325.

McDonnell, J. (1993). Judgments of personal responsibility for HIV infection: An attributional analysis. Social Work, 38, 403.

McDonnell, M. & Kessenich, C. (2000). HIV/AIDS and women. Lippincott's Primary Care Practice, 4(1), 66-73.

McLeod, A. (1997). Aboriginal Communities and HIV/AIDS: Final Report. A Joint Project with the Canadian AIDS Society and the Canadian Aboriginal AIDS Network.

Mill, J. (1997). HIV risk behaviors become survival techniques for aboriginal women. Western Journal of Nursing Research, 19, 466-489.

Minh-ha, T.T. (1989). Woman, native, other. Writing postcoloniality and feminism. Indianapolis, IN: Indiana University Press.

Minh-ha, T.T. (1991). When the moon waxes red. Representation, gender and cultural politics. New York: Routledge.

Mishler, E. (1979). Meaning in context: Is there any other kind? Harvard Educational Review, 49, 1-19.

Mishler, E. (1986). Research interviewing: Context and narrative. Cambridge, MA: Pennsylvania Press.

Moneyham, L., Seals, B., Demi, A., Sowell, R., Cohen, L., & Guillory, J. (1996 a). Perceptions of stigma in women infected with HIV. AIDS Patient Care and STDs, 10, 162-167.

Moneyham, L., Seals, B., Demi, A., Sowell, R., Cohen, L., & Guillory, J. (1996 b). Experiences of disclosure in women infected with HIV. Health Care for Women International, 17, 209-221.

Mullen Sand, K. (1992). Indian women's personal narrative: Voices past and present. In Culley, M. (Ed.). American women's autobiography. Fea(s)ts of memory (pp. 268-294). Madison, WI: University of Wisconsin Press.

Neuman, A. (1997). Ways without words: Learning from silence and story in post-holocaust lives. In A. Neuman and P. L. Peterson (Eds.), Learning from our lives (pp.91-120). New York: Teachers College Press.

Nicholas, S. & Schilder, E. (1997). The lived experiences of Winnipeg women with HIV/AIDS. AIDS Patient Care and STDs, 11, 86-92.

Oakley, A. (1981). Interviewing women: A contradiction in terms. In H. Roberts (Ed.), Doing feminist research (pp. 30-61). London: Routledge.

Ochberg, R. (1994). The narrative study of lives. California: Sage.

O'Neil, J.D. (1993). Report form the roundtable. In Royal Commission on Aboriginal Peoples. The path to healing. Ottawa, ON: Minister of Supply and Services Canada.

O’Neil, J. D., Reading, J. R., & Leader, A. (1998). Changing the relations of surveillance: The development of a discourse of resistance in aboriginal epidemiology. Human Organization, 57(2), 230-237.

Orr, J. (2001). Researching First Nations educators through presence, collaboration, and advocacy. In A. L. Cole & J.G. Knowles (Eds.). Lives in context. The art of life history research (pp. 192-207). Walnut Creek, CA: AltaMira Press.

Paget, M. (1983). Experience and knowledge. Human Studies, 6, 67-90.

Pillsbury, G. & Shields, C. (1999). Shared journeys and border crossings. When they become we. Journal for the Just and Caring education 5(4), 410-430.

Pinch, W. (1994). Vertical transmission in HIV infection/AIDS: A feminist perspective. Journal of Advanced Nursing, 19, 36-44.

Poirier, S. & Ayres, L. (1997). Focus on qualitative methods. Endings, secrets, and silences: Overreading in narrative inquiry. Research in Nursing & Health Care, 20, 551-557.

Poitras, J. A. & Rivet, R. (1999). Osopikahikiwak. Paris: Services culturels de l”Ambassade du Canada.

Rich, A. (1979). On lies, secrets, and silence: Selected prose, 1966-1978. New York: Norton.

Richardson, L. (1995). Narrative and sociology. In J. van Maanen (Ed.). Representation in ethnography (pp. 198-221). Thousand Oaks, CA: Sage Publications.

Riessman, C. (1993). Narrative analysis. Newbury Park, CA: Sage.

Romero, M., & Stewart, A. J. (1999). Women's untold stories: Breaking silence, talking back, voicing complexity. New York: Routledge.

Rugg, L.H. (1997). Picturing ourselves: Photography and autobiography. Chicago: The University of Chicago Press.

Said, E. (2000). Bursts of meaning. In E. Said. Reflections on Exile and other essays (pp. 148-152). Cambridge, MA: Harvard University Press.

Sandelowski, M. (1991). Telling stories: Narrative approaches in qualitative research. Image: Journal of Nursing Scholarship, 23 (3), 161-166.

Sarna, L., Servellen, G., Padilla, G., & Brecht, M. (1999). Quality of life in women with symptomatic HIV/AIDS. Journal of Advanced Nursing, 30, 597-605.

Schultz, R. (1997). Interpreting teacher practice … two continuing stories. New York: Teachers College Press.

Semple, S., Patterson, T., Temoshok, L., McCutchan, A., Straits-Troester, K., Chandler, J., & Grant, I. (1993). Identification of psychobiological stressors among HIV-positive women. Women& Health, 20, 15-36.

Sharts-Hopko, N., Regan-Kubinski, M., Lincoln, P., & Heverly, M. (1996). Problem-focused coping in HIV-infected mothers in relation to self-efficacy, uncertainty, social support, and psychological distress. Image: Journal of Nursing Scholarship, 28, 107-111.

Ship, S.J. & Norton, L. (2000). "It's hard to be a woman!" First nations women living with HIV/AIDS. Native Social Work Journal, 3, 73-89.

Siegel, K. & Schrimshaw, E.W. (2000). Perceiving benefits in adversity: Stress-related growth in women living with HIV/AIDS. Social Science & Medicine, 51, 1543-1554.

Smith, L.T. (1999). Decolonizing methodologies. Research and indigenous peoples. New York: Zed Books Ltd.

Smith, S.M. (1998). On the pleasures of ruined pictures. In A. Banks & S.P. Banks (Eds.). Fiction and social research (pp. 179-194). Walnut Creek, CA: Altamira Press.

Smith Percy, M. (1994). Children who are homeless describe what is special: A photographic heuristic study. South Carolina: University of South Carolina.

Solanke, A. (1991). Complex, not confused. In J. Spence & P. Holland (Eds.). Family snaps. The meaning of domestic photography (pp. 128-138). London: Virago.

Sontag, S. (1977 *and 1989- paperback*). On photography. New York: Double Day.

Spence, J. (1990). 'No I can't do that, my consultant wouldn't like it.' In Camerawork. Silent health: Women, health and representation (pp. 73-85). London: EGA.

Spence, J. (1995). Cultural sniping: The art of transgression. London: Routledge.

Spittal, P. M., Craib, K.J.P., Wood, E., Laliberte, N., Li, K., Tyndall, M.W., O'Shauhnessy, M.V., Schechter, M.T. (2002). Risk factors for elevated HIV incidence rates among female injection drug users in Vancouver. Canadian Medical Association Journal, 166(7), 894-899.

Stevens, P. (1996). Struggles with symptoms. Women's narratives of managing HIV illness. Journal of Holistic Nursing, 14, 142-161.

Stevens, P.E., Doerr, B.T. (1997). Trauma of discovery: Women's narratives of being informed they are HIV-infected. AIDS Care, 9(5), 523-539.

Stewart, K.C. (1996). An occupied place. In S. Feld & K.H. Basso (Eds.). Senses of place (pp. 137-165). Santa Fe, NM: School of American Research Press.

Tafoya, T. (2000). Unmasking dashkayah: Storytelling and HIV prevention. American Indian and Alaska Native Mental Health Research, 9(2), 53-65.

Touliatos, J. & Compton, N. (1988). Approaches to child study. Minneapolis, MN: Burgess Publishing Company.

Trinh Minh-Ha, T. (1989a). Woman native other. Bloomington, IN: Indiana University Press.

Trinh Minh-Ha, T. (1989b). Not you/like you: Postcolonial women and the interlocking questions of identity and difference. In G. Anzaldua (Ed.). Making face, making soul. Haciendo Caras (pp. 371-420). San Francisco, CA: Aunt Lute Foundation Books.

Trussler, T. & Marchan, R. (1997). Field guide: Community HIV health promotion. Ottawa, ON: Health Canada/AIDS Vancouver.

University of Manitoba, Northern Health Research Unit (1998). Research on HIV/AIDS in aboriginal people: A background paper. Health Canada, Medical Services Branch. Available: http://www.hc-sc.gc.ca/msb/fnihp/hivpaper.htm.

van Loon, R. A. (2000). Redefining motherhood: Adaptation to role change for women with AIDS. Families in Society: The Journal of Contemporary Human Services, 81(2), 152-161.

Van Uchelen, C.P., Davidson, S.F. , Quressette, S.V.A., Brasfield, C.R., & Demerais, L.H. (1997). What makes us storng: Urban aboriginal perspectives on wellness and strength. Canadian Journal of Community, 16(2), 37-50.

Wagner, D. (1994). Beyond the pathologizing of nonwork: Alternative activities in a street community. Social Work, 39(6), 718-727.

Wagner, J. (1979). Images of information. Still photography in the social sciences. Beverly Hills, CA: Sage.

Wang, C. & Burris, M.A. (1994). Empowerment through photo novella: Portraits of participation. Health Education Quarterly, 21(2), 171-186.

Webster, S. (2000). Introduction. Native Social Work Journal, 3, 9-14.

Weiser, J. (1975). PhotoTherapy: Photography as a verb. PhotoTherapy, 4(2), 33-36.

Weiser, J. (1983). Using photographs in therapy with people who are 'different'. In D. Krauss & J. Fryrear (Eds.). Phototherapy in mental health (pp. 175-199). Springfield, IL: Charles Thomas Publisher.

Weiser, J. (1988). "See what I mean?" Photography as nonverbal communication in cross-cultural psychology. In F. Poyatos (Ed.), Cross-cultural perspectives in nonverbal communication (pp. 245-290). Toronto, ON: Hogrefe.

Weiser, J. (1990). More than meets the eye: Using ordinary snapshots as tools for therapy. In T. Laidlaw, C. Malmo, & Associates (Eds.). Healing voices: Feminist approaches to therapy with women (pp. 83-117). San Francisco: Jossey-Bass.

Weiser, J. (1993). PhotoTherapy techniques. Exploring the secrets of personal snapshots and family albums. San Francisco: Jossey-Bass.

Weiser, J. (1996). Psychosocial consequences of living with HIV/AIDS – Or, what I learned from my clients and friends. The Social Worker, 64(4), 18-33.

Weiser, J. (1998). Taking the medicine wheel to the street. In W. Rowe & B.Ryan (Eds.). Social work and HIV. The Canadian experience (pp. 160-182). New York: Oxford University Press.

Weiser, J. (2001). PhotoTherapy techniques: Using clients' personal snapshots and family photos as counseling and therapy tools. Afterimage, 29(3), 10-15.

Wiener, L. (1991). Women and human immunodeficiency virus: A historical and personal psychosocial perspective. Social Work, 36, 375-378.

World Health Organization (1992). Why women and HIV? It takes two to tango. AIDS Health Promotion Exchange, 3, 1-3.

Yalom, M. (1993). A review of social science and the self and getting personal. Signs: Journal of Women in Culture and Society, 18(2), 455-458.